

## **I. Introduction**

Even before I established Advocacy for Patients with Chronic Illness, Inc., fellow patients came to me with a broad range of legal questions – questions about health and disability insurance, Social Security Disability (“SSDI”), discrimination in employment and public accommodation, and medical leave. In addition, because patients are dependent on both doctors and lawyers, at least to some extent, in navigating the legal landscape, they, too, need to better understand the way the various areas of law work in the context of chronic disease. This *Handbook* is intended to provide general information for patients, doctors, lawyers, family members, and even patients’ employers and schools.

If, as the great philosophers said, knowledge is power, then this *Handbook* will give you both the knowledge and the power to navigate the various legal issues faced by patients, from insurance, to Social Security disability, to employment discrimination.

The *Handbook* addresses seven main areas of law, with a sprinkling of smaller, but equally important, pieces of advice and information.

The first issue addressed in the *Handbook* is how patients can obtain their own medical records. In addition to providing general information in the text, Appendix A summarizes each state law relating to getting medical records.

The second area of law covered in this *Handbook* pertains to private health insurance, including how to get and keep insurance, as well as how to appeal a decision from your insurance company not to pay for a treatment or procedure your doctor has prescribed. This expanded section also explains different types of health insurance that might be available for those of us with chronic illness, including high-risk pools, guaranteed issue, COBRA conversion, prescription drug patient assistance programs, and others. We’ve also added new rules that have come about as a result of health reform.

The third main category is private disability insurance, with an emphasis on what to do if your claim for disability is denied or discontinued.

The fourth main area is Social Security Disability. This section of the *Handbook* is intended to assist patients who apply for Social Security to learn the system, using a step-by-step approach to each level of decision-making, from the initial application all the way to the courts.

Fifth, the *Handbook* discusses discrimination in employment and public accommodation, as well as medical leave. It includes a detailed discussion of the Americans with Disabilities Act, or ADA, in the employment context, as well as in the context of public accommodations (i.e., restaurants, stores, etc.). The *Handbook*’s thorough analysis of employment discrimination allows each patient to determine whether he or she meets the standards for coverage under the ADA, and what accommodations his or her employer can, should, and may be required to make.

Also in the discrimination section is a discussion of the Family & Medical Leave Act, or the FMLA, for patients and their families who need to take time off from work to deal with disease-related issues.

Sixth, the *Handbook* provides a detailed section on the education-related laws for both lower grades through high school, and for college and graduate schools, as well. There's also a section on the obligations of private schools.

Finally, there is a brief section on the Fair Housing Act. We have gotten a few housing questions over the past couple of years and decided to provide you with a summary of some of the provisions of the federal law protecting disabled persons from discrimination in housing.

There also are smaller sections on Emergency Assistance and working with doctors to help them help us to get what we need in order to obtain benefits.

Perhaps even more useful are the *Handbook's* appendices. Not only is there a summary of every state law relating to how to obtain medical records, but there are sample health and disability appeal letters, sample SSDI application papers, and much more. There even is an appendix outlining what employers can and cannot say, ask or do in a job interview.

There are a number of issues as to which the law differs from state to state. The information provided here is general, but not universal. You may need to contact a state agency or private attorney to ascertain the law in your State on a particular issue. For questions about health and disability insurance, contact your State's Insurance Department. For questions about discrimination of any kind, see your State's civil rights agency or the federal Equal Employment Opportunity Commission, [www.eeoc.gov](http://www.eeoc.gov). In each section, we have provided contact information for other such resources so that you can find out even more about the issues you confront.

## **II. How to Navigate this Handbook: Brief Questions and Answers**

Because so many of us find the law to be complex and even intimidating, I have made an effort to present things in a reader-friendly fashion. However, if the Table of Contents and the Introduction still leave you wondering where you can find the answers you are looking for, this section will use a Question and Answer format to direct you to the applicable section of the *Handbook*. Please note, however, that the Answers provided in this section are summaries that omit many important details. You should read the sections of the *Handbook* referred to in the Answers in their entirety for a full discussion of the subject area.

*Question:* I have asked my doctor for a copy of my records and he refuses to give it to me. What are my rights?

*Answer:* Each state has a slightly different law instructing individuals how to get their medical records. The *Handbook's* state-by-state review of those laws is found in Appendix A, and Appendix B provides a sample request for medical records. In general, a patient is entitled to inspect and copy his or her records. However, doctors are allowed to

charge a per-page copying fee, and, in some states, a fee for pulling the file and postage. Generally, your request for records must be in writing. If you have an attorney or other representative gathering records on your behalf, they will need a signed release from you allowing them to access your medical records. What to do if your doctor refuses to provide you with your records, even if you follow your state's law to the letter, is discussed more fully in Section III of the *Handbook*.

*Question:* I have lost my job. How do I keep my health insurance for as long as possible?

*Answer:* Federal law requires that you be offered continuation coverage, called COBRA, for 18 months or longer as long as your employer had 20 or more employees in the preceding year. The key, though, is ensuring that you do whatever it takes to avoid a pre-existing condition limitation when you obtain new insurance so that medical interventions relating to your disease are covered at all times. That means that you must obtain new employment-based group health insurance within 63 days of a loss of coverage. Section V.A.ii of the *Handbook* discusses COBRA, pre-existing conditions limitations, and other avenues to obtain health insurance for people with a chronic illness. Much of this will change in 2014, when, under the health reform law, all insurance will have to be sold without regard to pre-existing conditions. Indeed, in some states, individual insurance already is sold without pre-existing condition exclusions or limitations. Check with your state Insurance Department for the law in your state.

*Question:* My doctor has prescribed a drug that my insurer says is not on the “formulary” for my insurance plan. What does this mean, and what do I do?

*Answer:* A formulary is a list of medications that are covered by your insurance plan. The first thing to do if you receive a notice that a medication you are taking is not covered by your insurance is to call your insurer and ask if there is a medical alternative that is on the formulary. If so, then go back to your doctor with this information and get him or her to write you a prescription for the alternative, medically equivalent drug – or help you explain to the insurance company why the alternative isn't really a medical equivalent. If your insurer is unable to identify a medically equivalent alternative, or your physician believes that the drug the insurance company covers is not a true medical equivalent, you and your doctor should appeal the denial of coverage for the prescribed drug. Section V.B discusses appeals processes, and Appendix C contains sample appeal letters, including appeals involving formulary issues.

*Question:* I don't have health insurance, I can't work, and I cannot get prescription drugs that my doctor says I need. What should I do?

*Answer:* Most pharmaceutical companies have compassionate care or patient assistance programs through which they give patients with dire financial need free medication for a period of time. Section V.C. explains how to find and use these programs.

*Question:* My disability insurance carrier has sent me a letter saying that my benefits are being discontinued because I no longer am disabled, but both my doctor and I disagree. What can I do?

*Answer:* You can appeal. The letter notifying you that your benefits were terminating should have contained instructions on how to appeal. The appeals process is discussed in detail in Section VI.C, below. By gathering your medical records, obtaining written support from your physician, and keeping a diary of your daily symptoms, you will have all the materials you need to launch an appeal. In addition, your insurer may require, or you may request, an Independent Medical Examination, which is discussed in Section VI.D, below. Sample disability insurance appeal letters can be found in Appendix D, along with a sample disability retirement appeal.

*Question:* I know I had a right to appeal my insurance company's decision, but I was too sick to do so in the time frame the insurer allowed. Do I still have recourse?

*Answer:* If you take anything away from this *Handbook*, let it be that you **must meet deadlines**. It is nearly impossible to resurrect an appeal if you have allowed the appeal time period to lapse. See Section IV, below. If you are too ill to provide a detailed appeal letter, then send a letter within the prescribed time frame indicating that you are appealing on whatever bases you feel are appropriate, and indicate that you are too ill to provide a detailed appeal at that time, but that you will do so as soon as you are able. Ask that they note that your appeal is timely, but that they hold the appeal in abeyance until you are able to compile a more detailed appeal.

*Question:* My doctor wants to help me obtain insurance coverage for what she is prescribing, but she doesn't know what she needs to say. Can you help us?

*Answer:* This *Handbook's* discussion of the various elements that should be addressed in each type of appeal should help physicians to know what issues to address. However, patients should be mindful of the fact that doctors don't get paid for the time they spend writing letters to insurance companies. There is much a patient can do to minimize the burden on physicians, enabling them to help their patients to get what they need. In addition to using the appropriate area of the *Handbook* to determine what issues a doctor should address, see Section XII on how patients and doctors can work together to ensure the best possible results.

*Question:* I don't have disability insurance and no longer can work. What can I do?

*Answer:* You may apply for Social Security Disability Income (SSDI). First, you must determine what your disabilities are. The Social Security Administration has criteria for each category of disorders. A "table of contents" of what is called the Blue Book – the listing of criteria – is found in Appendix F. If, in addition to a primary chronic illness, you suffer from any other conditions that contribute to your inability to work, you should find the criteria for each of your disabilities and make every effort to explain your symptoms in the context of those criteria. There is more to obtaining



SSDI than just showing that you are ill. SSDI is given only if there are no jobs in the economy that you could perform. You have to make it clear that, not only are you sick, and not only can you no longer do the job you had when you became too ill to work, but you also cannot perform any other job that is available in the economy. These criteria are explained in more detail in Sections VII.C through E, and a sample SSDI application is contained in Appendix G.

*Question:* I am twenty years old and disabled, but I have been told that I am not eligible for SSDI. Is this right? What can I do?

*Answer:* You are not eligible for SSDI unless you have enough service credits. Typically, this means you have to have paid into the system through FICA tax deductions from your paycheck (or through payment of estimated quarterly tax if you are self-employed) for 40 quarters – typically, ten years – with 20 of those quarters in the most recent 10 years. See Section VII.C for details. If you do not satisfy this requirement, you should consider applying for “SSI,” Supplemental Security Income. This benefit is available to disabled people who do not qualify for SSDI. You must be disabled and meet the very low income test to get SSI. The good news is that, if you qualify, you will get Medicaid as well as a cash benefit. Medicaid provides very good coverage – in some ways, better than most commercially available health insurance. See Section VII.F. for more information.

*Question:* My employer is making new and unreasonable demands on me, and I believe that the intent is to find an excuse to fire me because I am sick. Does the law protect me?

*Answer:* To be protected by the Americans with Disabilities Act (ADA), assuming your employer is covered, you must be disabled according to the Act’s definition of “disability,” i.e., you have a physical or mental impairment that substantially limits one or more major life activity. Major life activities include, but are not limited to, seeing, hearing, speaking, walking, breathing, and bodily functions like digestion, bowel, and immune functions. In addition, you must be able to perform the essential functions of the job, i.e., the fundamental duties of the position you are in, either without any accommodation, or with a reasonable accommodation, which is an accommodation that would not create an undue hardship on an employer. For example, if you are an editor at a publishing company, reading and editing would be essential, whereas photocopying and mailing your edited work to an author may not be, as long as the employer is sufficiently large that transferring these functions to another employee does not create an undue hardship. Further, if the vast majority of your work as an editor can be performed at home, allowing you to work at home at least some of the time may be a reasonable accommodation, as long as you are not needed at the workplace to meet with authors, attend staff meetings, and the like. In other words, the answer to your question requires a case-by-case analysis of your medical condition, the nature of your job, and the ability of the employer to make accommodations without creating an undue hardship. Each step in the analysis of an ADA claim is discussed in detail in Section VIII.A.

*Question:* My 8 year old daughter has Crohn's disease and I need to be able to take time off when she is particularly ill, as well as to accompany her to doctor appointments, diagnostic tests, and treatments. My employer has said that, if I do not improve my attendance, I will lose my job. What can I do?

*Answer:* The Family and Medical Leave Act (FMLA) provides that employers with more than 50 employees must grant 12 weeks per year of unpaid leave to care for oneself or an immediate family member, including a child. As a general rule, if you have been working for this employer for at least 12 months, you are entitled to FMLA leave. Although FMLA leave is unpaid, an employer may require or permit an employee to use all accrued vacation, sick, or other paid leave time during an FMLA leave. You must give your employer as much notice as possible of your FMLA absences, and your employer can require a medical certification (although you are not required to provide medical records to an employer to justify an FMLA leave). See Section VIII.B for a fuller discussion of the FMLA.

*Question:* My child's school will not provide assistance when my child is too sick to go to school. I have asked for a tutor at home, but the school says they can't respond quickly to such requests, so that, if my child is at home for a week and then goes back to school, the school says it would be unable to respond in such a short time frame. What are my rights and those of my child?

*Answer:* The school has an obligation to identify all children with disabilities and to work with the parent to design a plan pursuant to which the child's disability can be accommodated. Every child has a right to a "free and appropriate public education." Part of that means creating a plan so that the probability of intermittent absences can be dealt with in a timely manner. For a fuller discussion of your child's right to educational equity, see Section IX.

*Question:* I have requested reasonable accommodation from my landlord in the form of a handicapped parking spot closer to my residence, but my landlord has refused my request. Do I have recourse?

*Answer:* The Fair Housing Act requires that landlords make reasonable accommodations for persons with "disabilities." The definition of "disability" is the same as under the Americans with Disabilities Act – you must be substantially impaired in a major life activity like walking, talking, breathing, eating, disposal of bodily waste, etc. If you meet that test, then a landlord must provide reasonable accommodations that do not constitute an undue burden. The majority of courts have found that this includes creating a close parking spot. For a fuller discussion of the Fair Housing Act, see Section X.

*Question:* I recently had to undergo emergency surgery, and as a result, I can't pay my rent this month. What do I do?

*Answer:* There may be an emergency assistance program in your area. Section XI provides some thoughts on how to tap into such resources. Since many of the emergency assistance programs are administered on the local level, it is impossible to find and list them all, so the *Handbook* focuses on how to search for emergency assistance programs in your area.

*Question:* I went to my doctor's office and the person at the front desk would not allow me to use the bathroom until I had filled out all the necessary forms and provided my insurance card. I told her I had Crohn's disease, and she still would not let me use the bathroom. What can I do?

*Answer:* There is much advocacy to be done outside the legal context. Every time we teach a person about a chronic illness, we make the world a more accepting place for all patients. See Section XIV for ideas on advocacy outside the legal context.

*Question:* It seems like you use different definitions of the word "disability" in different contexts. You talk about "own occupation" or "any occupation" in the context of disability insurance; the ability to perform any job in the economy in the context of Social Security; and whether the patient is substantially impaired in performance of a major life activity in the context of the ADA and Section 504 of the Rehabilitation Act as applied to employment, schools, and housing. How do I know if I have a disability?

*Answer:* You're absolutely right. The definition of "disability" differs in different contexts. In the context of a commercial disability insurance policy, you have to look at the policy to see what definition they are using; this is explained in greater detail in Section VI, below. In the context of Social Security, you must either meet a listing or be unable to perform any job available in the economy; this is explained in greater detail in Section VII, below. In the context of the ADA or Section 504, whether for employment, schools, or housing, you must show that you are substantially impaired in the performance of a major life activity to show you are disabled; this is explained in greater detail in Sections VIII (employment), IX (schools), and X (housing), below. It is NOT the case that a particular disease is always going to be considered a disability in all contexts. In every context, whether a person is disabled will depend on the functions the person is able or unable to perform, and this may change from time to time with chronic illness. The definition of "disability" is explained in detail in each context discussed below, so go to the section that pertains to the issue with which you are grappling and focus your attention there.

### **III. Your Medical Records**

Most States have a law pertaining to a patient's right to his or her own medical records. A summary of these statutes is set forth in Appendix A. In general, you are entitled to inspect and copy your records, although your doctor is allowed to charge a fee for copying and, in some states, for pulling the file and postage. State law usually determines the amount of the copy fee. Generally, you must request a copy of your records in writing. If you have an attorney who is

gathering your records on your behalf, your attorney will need to present a release signed by you entitling your attorney to obtain your records.

Although most state statutes provide a time frame during which a provider must respond to a request for medical records, getting your medical records together can be a time consuming step in the process. Do not delay in requesting your records, and after you have made the request, follow up every few days until you or your attorney has the records. Get everything, including diagnostic test reports, lab work, etc. Indeed, collecting your medical records as you go is highly recommended. I try to get copies of every lab report, pathology report, and surgical report, and I have never had a doctor balk at giving me a copy of what's in their file when I ask for each record one at a time.

However, every once in awhile, I hear of a doctor who will not release a patient's medical records to the patient. In many states, the governing statute provides an exception for circumstances in which the treating physician believes disclosing the records would be harmful to the patient. However, in almost every one of those states, either the records must be provided to another physician or the patient's representative, and/or the physician must provide his or her reasons for refusing to disclose in writing, and there is a process for contesting the treating physician's determination.

If your doctor refuses to provide you with records in a timely manner, it may help to remind the doctor that you do have rights. If you know an attorney who will help you, get him or her to write a letter to the doctor on your behalf, citing your State's law on medical records (again, *see* Appendix A). If you don't know an attorney, or can't afford one, write a letter to your doctor citing the law and following that law's instructions, as set forth in Appendix A, and keep a copy for your file. A sample letter can be found in Appendix B. If your doctor refuses to provide the documents or does not respond to your request, see Appendix A for your state's law to determine whether you are entitled to a written denial from your doctor, with his or her reasoning. Then determine whether your state law provides further recourse. If it does, you can pursue that. As a last resort, you can make a report to the state agency that governs the licensing of physicians, or to your state's Attorney General.

Finally, the federal law known as HIPAA protects patient privacy by requiring that certain elements be included in any authorization you give a third party to obtain your medical records. A valid HIPAA release will satisfy the laws of each state. So if you want to give someone else permission to obtain your medical records, make sure to include each of the following in the authorization you provide:

- Your name, date of birth, and signature;
- An identification of the person to whom you are releasing information;
- An identification of the materials to which you are allowing a third party access (for example, all medical records);
- The time frame during which the release will remain in effect;
- A statement of your right to revoke the release in writing, and a statement that any such revocation will not harm those who have relied on the release in the meantime;



- A statement that the provision of health care is not conditioned on you signing the release, nor will you suffer any retaliation if you revoke the release;
- A statement that the information disclosed may lead to re-disclosure (for example, if you authorize me to get your medical records, I will then send at least some of them to an insurance company in support of your appeal); and
- A statement that you have read and understand the release.

If you wish to give a third party access to your medical records, you need to sign a document that includes these elements. Many doctors' offices and other health care providers maintain a form you can use for this purpose, as does Advocacy for Patients with Chronic Illness.

#### **IV. A Note About Time Periods**

Rule number 1: Once you blow a time limit, you lose. No exceptions, no appeals, no recourse. If your insurer sends you a denial that says you have 60 days to appeal and you wait until day 61, you are finished. The same is true of SSDI, the Americans with Disabilities Act ("ADA"), and any other time limits established by law.

If you are waiting for medical records or a letter from your doctor or some other material you wish to submit in support of your claim, go ahead and file within the time frame, and note that you are expecting additional information, which you will submit as soon as possible. Ask them to hold the appeal in abeyance until you provide the additional information. Once you submit your timely appeal letter, you can continue to submit new information. But you cannot fail to appeal in a timely manner – period.

#### **V. Private Health Insurance**

People with a chronic disease need to know certain basic facts about health insurance: first, how to obtain insurance that covers chronic illness, including a discussion of high risk pools, COBRA and COBRA conversions, and mandated or guaranteed issue policies; second, how to get the insurance company to cover what we need; and third, how to file an appeal. This section will address those concerns. In addition, this section will include a discussion of prescription drug patient assistance programs that help low income patients to obtain their medications for free.

##### **A. How to Obtain (and Keep) Health Insurance**

I don't have a whole lot of rules for you, but here's the second one. Rule number 2: If you have health insurance through an employer, NEVER let it go unless and until you get new insurance through a new employer, or you leave the employer and your COBRA expires. No other health insurance will be as good or as affordable – at least until 2014, when, under the health reform law, there will be no more pre-existing condition exclusions at all.

A lot of changes that are part of health reform already are in effect. **Two caveats.** The **effective date of these changes varies with your plan.** The following changes took effect on

September 23, 2010 or the start of the next plan year after that date. For example, if you are in a group plan that works on a calendar year basis beginning on January 1, then these changes take effect for you on January 1, 2011 -- the beginning of the next plan year after September 23, 2010. If you are in an individual plan that renews on March 1, then the changes take effect for you on March 1, 2011 -- the beginning of the next plan year after September 23, 2010.

Second, **some provisions do NOT apply to "grandfathered" plans**. If you have a plan that existed on March 23, 2010 and does not change in any substantial way (keep reading), it is a grandfathered plan. A plan loses its grandfathered status if it changes in one of the following ways:

- (a) increased copayment of more than \$5 or above medical inflation plus 15 percentage points;
- (b) increased deductible above medical inflation plus 15 percentage points; increased out-of-pocket limit above medical inflation plus 15 percentage points;
- (c) an increase in coinsurance rates;
- (d) a decrease in the annual limit or adoption of a new annual limit after March 23, 2010;
- (e) a decrease of more than 5 percentage point below the existing employer contribution rate as of March 23, 2010; or
- (f) the elimination of all or substantially all covered benefits to diagnose or treat a particular condition after March 23, 2010.

Any new plan is **NOT** a grandfathered plan, so if your employer switches to a different insurance company, or if you buy a new individual policy after March 23, 2010, that plan is **NOT** grandfathered.

As I go through each of the changes that took effect on September 23, 2010 or will take effect at the beginning of the next plan year after that date, **I will indicate which ones apply to grandfathered plans and which do not**.

- Young adults can stay on their parents' health plans to age 26. This **DOES** apply to grandfathered plans, but if the young adult become eligible for group insurance through a job, he or she becomes ineligible to stay on his or her parents' plan.
- There are no more pre-existing condition exclusions for children under 19 years of age. This **DOES** apply to grandfathered group plans, but it does **NOT** apply to grandfathered individual plans.
- Preventive services are covered for free. There are no copays or coinsurance for preventive services. This only works if your doctor bills the preventive care under a separate code or if you go to the doctor visit only for preventive care. This does **NOT** apply to grandfathered plans.
- Annual limits are only allowed if they are reasonable. Reasonable annual limits are: \$750,000 for the plan year beginning on or after September 23, 2010 but before September 23, 2011; \$1.25 million for the plan year beginning on or after September 23, 2011 but before September 23, 2012; and \$2 million for the plan year beginning on or

after September 23, 2012 but before January 1, 2014, at which point annual limits will not be allowed at all. This **DOES** apply to grandfathered group plans but does **NOT** apply to grandfathered individual plans.

- Lifetime limits are not allowed -- period. This **DOES** apply to all grandfathered plans.
- Health plans are not allowed to rescind (essentially, cancel) your insurance retroactively because you got sick, unless you committed fraud on your application. This **DOES** apply to all grandfathered plans.
- Women have direct access to ob/gyns without a referral; pediatricians can be classified as primary care providers; enrollees have a choice of primary care provider. This does **NOT** apply to grandfathered plans.
- No prior authorization requirement for emergency care, and no higher cost-sharing for out-of-network emergency care. This does **NOT** apply to grandfathered plans. It's also somewhat illusory; you can be balance billed by an out-of-network emergency room/doctor, so if your insurance pays less than the billed amount, you may be responsible for the rest of the bill.
- There are new rules governing insurance appeals. See below. These do **NOT** apply to grandfathered plans.

All of these provisions took effect on September 23, 2010 or will take effect at the start of the next plan year after that date. This takes effect in every state, regardless of your insurance company, unless you are in a high risk pool. These rules apply only to plans sponsored by an employer or issued by an insurance company, not to high risk pools. (See below for more about high risk pools).

#### i. Types of health insurance plans.

For patients with chronic illness, getting individual insurance is more difficult every day. If you cannot obtain insurance through an employer, then you should be looking for some other type of group insurance. Your focus should be on whether there is a pre-existing condition limitation and, if so, its duration.

If you are enrolled in an employer-based group plan with 20 or more employees, and you switch to another employer-based group plan with 20 or more employees, your health insurance cannot exclude or limit coverage of pre-existing conditions as long as your previous employer-based coverage terminated within fewer than 63 days of commencing your new insurance. However, if you have a break in coverage of longer than 63 days, even an employer-based group insurance plan can impose a pre-existing condition waiting period up to one year. In addition, individual or association-based health insurance plans can and do exclude pre-existing conditions, some for a waiting period, and some entirely, or they simply will not write a policy for a person with a pre-existing condition.

Here is the important language: You are “**HIPAA eligible**” if (1) you have had 18 months of continuous “**creditable coverage**,” the last day of which was under an employment-based group health plan; (2) you have used up COBRA or other continuation benefit; (3) you are not eligible for group health insurance, Medicaid or Medicare; (4) you do not have health insurance; and (5) you apply for coverage based on HIPAA eligibility within 63 days of the termination your prior coverage. If you are HIPAA eligible, you must have at least two “**guaranteed issue**” options. “Creditable coverage” includes private insurance, Medicaid, Medicare, state high risk pools, federal employee insurance, military insurance, the Children’s Health Insurance Program, and student health insurance.

States have complied with the requirements of HIPAA in a number of different ways. HIPAA does not require that all HIPAA eligible individuals be offered the same coverage as long as they are offered some coverage. States take a number of approaches, or a combination of approaches. The federal fall-back position is the individual market carriers must offer either their two most popular plans, a high deductible and a low deductible plan, or all of their plans.

For example, many states have **high-risk pools** for people who are chronically ill. These tend to be very expensive, and many exclude pre-existing conditions for 6 or 12 months for non-HIPAA eligible individuals. Appendix E is a table of the high-risk pools and how to reach them. Most of these are not limited to HIPAA eligible people, but in some states, HIPAA eligible individuals are permitted to enroll in the state’s high-risk pool without a pre-existing condition limitation. If you are not HIPAA eligible, your state’s high-risk pool may have a pre-existing condition waiting period.

Even better, if you have gone six months without insurance and have a pre-existing condition, you are eligible for the **Pre-existing Condition Insurance Plan (PCIP)**, created by the health reform law. These are essentially “high risk pools” that were created to bridge people with pre-existing conditions to 2014, when pre-existing condition exclusions will be prohibited. These are comprehensive plans with very reasonable premiums – much less expensive than the old state high risk pools. You can learn more about the PCIP in your state here: <http://www.healthcare.gov/law/provisions/preexisting/index.html>.

There are at least two other kinds of health insurance policies to look for if you are HIPAA eligible. Some companies that offer group health insurance will sell an individual what is called a COBRA **conversion policy** or just a conversion policy. What that means is that they allow you to convert your group policy into an individual policy either immediately upon leaving the group or upon expiration of the COBRA coverage. These policies don’t have the greatest coverage and they tend to be expensive, but they are one of the few ways to get an individual plan without a pre-existing condition limitation. For HIPAA eligible individuals, there would be no pre-existing condition limitation.

Some states have what are called “**guaranteed issue**” plans in addition to the plans that are guaranteed issue under HIPAA. These policies vary from state to state. That means that the state legislature has determined that any insurance company doing business in the state must offer a health insurance plan to anybody in need. These guaranteed issue plans tend to be the bare minimum, although some are just fine. The majority provide what is known as



“catastrophic coverage” or “major medical,” which means that the plan covers a hospital stay. Even if these plans cover prescription drug benefits, there can be an annual maximum of \$500 to \$1,000 per year. However, in some states, these plans are fairly good and reasonably priced. Do as much investigating before you have a crisis as is possible.

Starting in 2014, when insurance becomes mandatory, there will be health insurance Exchanges, marketplaces where you can shop for health insurance, compare plans and premiums, and purchase insurance. There will be no more pre-existing condition exclusions. Some states will operate two Exchanges, one for individual policies and one for small groups; other states will merge the two. The Exchanges will also be the place where you can apply for advance payment premium tax credits to help you pay for insurance if you can’t afford it on your own. States have a lot of flexibility in setting up their Exchanges; some will list any insurance plan that wants to be listed, whereas others will become active purchasers, making sure consumers have a good mix of plans at reasonable rates. Most states are already working on their Exchanges, which have to go live by October 2013, when you will be able to begin to enroll for plans effective January 1, 2014.

If you are not employed, are self-employed, or your employer does not provide health insurance, and you are not HIPAA eligible, you have a number of options, none of them great. I am not aware of any individual policy anywhere that will not exclude a pre-existing condition. However, you may find a policy with a six-month exclusion, for example, and then you would need to piece together something for only six months, which can be done through discount plans and other benefits available to the public at large.

In some jurisdictions, if you are self-employed, you may be able to cover yourself as an employee in a one-person group. Call your state Insurance Department to find out whether one-person groups are authorized in your state. In the alternative, you may be able to join a local Chamber of Commerce and enroll in their group plan. The National Association of Self-Employed has a plan that is not very good and very expensive, but it is there. Many trade associations also have group plans, and if you are older, the AARP has group plans. If you are not working due to disability, you may be eligible for public assistance-based health plans (i.e., Medicaid or Medicare). Check with the state agency in charge of Medicaid or the Social Security Administration for information about those programs.

A pretty good state-by-state source of what is available in each state is found at [www.healthinsuranceinfo.net](http://www.healthinsuranceinfo.net).

Look at these plans very carefully. You know what your largest medical expenses are likely to be. Make sure the benefits are adequate for your needs.

Watch, too, for policies that charge coinsurance instead of copays. Instead, they are more of a cost-sharing arrangement in which you pay 20 or 30% of everything, including prescription drugs, with a “stop-loss” or out-of-pocket maximum, after which point the insurer pays 100%. The stop-loss can be many thousands of dollars, requiring that you spend that amount every year before the insurer foots the bill in its entirety. If your health care costs are high on a regular basis, this sort of plan can break the bank.

If you have a co-insurance plan, you may need help with co-pays. If you have a plan that pays 80% and you are on Remicade or IVIg (two infusion drugs), which might cost upwards of \$5,000 per month, the co-pays can be devastating – \$1,000 per month or \$12,000 per year. There are several co-pay relief plans:

- The Patient Advocate Foundation Co-Pay Relief program <http://www.copays.org/>;
- The Patient Access Network Foundation. <https://www.patientaccessnetwork.org/>;
- The Chronic Disease Fund. <http://www.cdfund.org/home.html>;
- The Healthwell Foundation. <http://healthwellfoundation.org/>; and
- The Assistance Fund. <http://theassistancefund.org/>.

There also are alternatives to full-blown health insurance if all other options have been exhausted. These are discount programs in which health care providers have agreed to participate. One such plan is called Best Benefits, and another is called Protective Health Options. I have not had any direct experience with these plans, but especially if you are riding out a pre-existing condition waiting period, a plan like this may provide the bridge you need – if, of course, they are willing to cover pre-existing conditions.

## ii. COBRA and Michelle's Law

Federal law requires that you be offered continuation coverage after you leave a job, at your expense. This law is called COBRA. COBRA kicks in when there has been a “qualifying event,” which includes the following: (1) the death of a covered employee; (2) the termination (other than due to gross misconduct) or a reduction of hours, of a covered employee’s employment (including the employment of a spouse or dependent under the employee’s plan); (3) divorce or legal separation of a covered employee from the employee’s spouse; (4) a covered employee (spouse, or dependent) becoming entitled to Medicare benefits; or (5) a dependent child ceasing to be a dependant child of the covered employee. An event is a qualifying event if it meets one of these criteria and it causes the covered employee, spouse, or dependent child to lose coverage.

If you elect COBRA when you leave a job, you have 18 months of coverage. COBRA can be extended to 29 months if you are disabled (i.e., if you have an award letter from the Social Security Administration). Former spouses (due to death or divorce of the covered employee), former dependents (due to the death of the employee), spouses and dependents who become eligible for COBRA due to the fact that the employee became eligible for Medicare, and formerly dependent children all are entitled to 36 months of COBRA coverage. You may also get an extension of up to another 18 months (or a total of 36 months) if a second qualifying event occurs during your initial 18 month COBRA period due to loss of a job.

COBRA benefits begin upon the occurrence of a qualifying event, although employers have 30 days to notify the plan administrator of the qualifying event, and the administrator has 14 days after it is notified to get you the necessary enrollment forms and other information. When you leave a job and intend to COBRA, stay on top of your former employer until you

receive the necessary information. I once left a job intending to COBRA, but I didn't get the necessary information for three months, at which time I owed three months of premiums, which was a lot of money to have to pay all at once. Federal law requires that the information be provided within 44 days (30 days for your employer to notify the COBRA administrator and 14 days for the COBRA administrator to provide election forms to you). Stay on top of it.

Note that COBRA does not apply to all employers. Small employer plans (fewer than 20 employees), the federal government employee plan, and certain church plans are not covered by federal law, although some states extend COBRA to small employers. In addition, if an employer-based health insurance plan is eliminated entirely (for example, if the employer goes out of business), then there are no COBRA benefits. Under federal law, there is no limit on an employer's ability to terminate a group insurance plan. If your employer sends a notice that your plan is being terminated, act quickly to find new insurance – you do not have a right to COBRA in that situation.

I always pay for COBRA benefits for a month overlapping with my new insurance to make sure there is no break, even though theoretically I shouldn't have to do so. Better safe than sorry when it comes to health insurance coverage for a person with a chronic illness.

In addition, effective October 9, 2009, a college student who takes a medically necessary leave of absence due to a serious illness or injury must be permitted to remain on his or her parent's health insurance for one year. The student must provide the insurer with a written certification by a treating physician stating that the student is suffering from a serious illness or injury and that the leave of absence is medically necessary. This is known as Michelle's Law.

### iii. Charity care and community health centers.

Although it is a well-kept secret, hospitals receive federal funding for what is called "uncompensated care." This is care administered to patients who cannot afford to pay. There have been a number of pending lawsuits brought by states charging that the pursuit of collection from poor patients violates a hospital's obligation to provide charity care. When you are being "dunned" by a hospital – when you are receiving multiple bills and threats of legal action – keep in mind that, if you are a genuine charity case, you should not be pressured for payment.

The easiest thing to do in such a circumstance is agree to pay some very small amount per month. In general, if you agree to pay \$20 per month and you keep up these payments, your case should not be sent on to collections. No judge will rule against you as long as there is a payment plan and you don't miss a payment.

Finally, you may wish to explore whether there are any Community Health Centers (CHC) in your location. These may also be called Federally Qualified Health Centers (FQHCs). CHCs provide help regardless of ability to pay. They are largely federally funded entirely separately from Medicaid and Medicare. It is not a perfect solution – they can't give you free medication, for example – but you can get help if you are in acute need. Pair this with a pharmaceutical drug patient assistance program (see below) and you may have a good enough safety net.

#### iv. A note about drug formularies.

These days, most insurance plans come with what is called a prescription drug “formulary.” This is a list of drugs that the insurance company will cover. For the most part, medication that is not covered by the formulary will not be covered by your plan, or will cost you a higher co-pay. It is very important for you to know what is on the formulary so that you and your doctor can prescribe accordingly. If there is a functionally equivalent medication on the formulary, your doctor should simply prescribe that drug instead of another (for example, if your formulary covers Prilosec instead of Prevacid, take Prilosec). If, however, a medically necessary drug is prescribed and there is no medical equivalent, you have a good argument for an appeal. See the next Section explaining your appeal rights, and Appendix C for sample appeal letters relating to formulary issues.

### **B. Coverage Issues & Appeals**

Once you have health insurance, the next hurdle is getting coverage for everything you need. Patients with chronic illnesses have to learn to advocate for themselves to obtain coverage for experimental medication and treatments, enteral or other nutrition delivery systems, certain diagnostic tests and treatments, and anything else the insurance company says is not covered under the policy or is not medically necessary.

The longer I do insurance appeals, the more I learn about how to do them. As a result, this section is greatly expanded.

#### i. Appealing a noncoverage decision.

Generally, health insurance covers “medically necessary” medicine, procedures, and treatments. However, some insurers take the position, for example, that enteral feeding is not medicine, but nutrition, and therefore not covered. Similarly, some insurers refuse to pay for B-12 shots because it is vitamin rather than medicine even though it is necessary for some patients because, like me, they have had part of their small intestine removed. Most health insurance policies exclude coverage for experimental drugs and treatments. It is this latter category of appeals that is the most challenging because you have to do medical research to prove that the particular item or treatment is supported in peer-reviewed medical literature.

Before going to court about a health insurance issue, you will have opportunities to appeal a noncoverage decision. In fact, you must go through the entire appeal process before you can go to court. The appeals you make to your insurance company are called internal appeals. Most plans allow two internal appeals, although some insurers are taking the position that the health reform law limited internal appeals to individual plans to only one appeal. This is not true; the law says there must be at least one internal appeal, not that the plan can’t offer a second level if it so chooses. In any event, you must start with your internal appeals before you can pursue any further steps.



The first thing you want to do is to be clear on why the insurer is denying coverage. If you receive an explanation of benefits (EOB) or a denial letter, under health reform, the procedure codes and diagnosis codes may not be included in your denial notice. You must be offered that information in the denial notice. If you are not certain of what is being denied, then you need to request this additional information. In addition, the denial letter you receive will contain language very similar to the following:

You may receive, upon request and free of charge, reasonable access to and copies of all documents, records and other information relevant to this request and an explanation of the scientific basis or clinical judgment that we relied upon in making our determination. This includes a copy of the internal rule, guideline, or protocol, if any, that we relied on in making the non-coverage decision for this request.

They must send you everything they relied on, even documents that you or your doctor sent them initially, so that you can have a full understanding of why they have denied coverage. If you make this request, you must do so in writing. You should keep a copy and send the request via certified mail. In addition, you should make it very clear that this request does NOT constitute the commencement of your appeal. The health reform regulations make it clear that requesting these materials cannot be counted as your appeal, but it's worth it to say it explicitly anyway.

When you are denied because the insurer believes the item is not medically necessary or is experimental/investigational, you should search your insurer's website to look for their medical policies, called clinical policy bulletins (CPBs). These are detailed papers written by or for insurers that outline all of the coverage policies, including citations to the medical journal articles and other sources your insurer relied on in making their decision. If you receive a medical necessity denial, the CPB will tell you what factors are considered in determining medical necessity. For example, we have an insurance appeal for a drug for treating a neurological illness. The CPB tells us that, to be medically necessary, certain blood test results must be abnormal, the patient has to have tried certain other treatments or diagnostics, and the symptoms must have persisted for a certain period of time. That tells you exactly what to point out in your medical records. It also allows you to research in medical journals to see if the criteria your insurer is using are really the right criteria. CPBs are usually found in the Provider section of the insurer's website. If you can't find them, or if your insurer doesn't publish them, you can and should request a copy before writing your appeal. Again, your request should be in writing and you should send it certified mail so you can prove that it was received.

If you are denied coverage for something you and your doctor feel you need, you should appeal. Believe it or not, more than 70% of health insurance appeals are successful. Sometimes, appealing is as simple as writing a letter. For example, whenever I change jobs, my new insurer denies coverage for B-12 shots that I need because I am missing my terminal ileum due to surgery. In each instance, I have written a letter and explained the reason I need B-12 shots, and it has been covered from then on. At other times, you will need your doctor to assist you in advocating with the insurer. Doctors should be willing to write a letter on your behalf. (See Section XII for suggestions for both patients and doctors). Even if your doctor writes, though,

you should write as well, and give them the patient's perspective. Again, sample appeal letters can be found at Appendix C.

Probably the most common misconception in health insurance appeals is that letters from either the patient or a doctor are enough. In simple cases, like my B-12 shots, that's true. But in the majority of cases, **letters are not sufficient**, especially in cases in which the insurer is arguing that the treatment is experimental or investigational. Although a letter from a doctor may help, without underlying medical records, the insurance company rarely will reverse itself in a complex case. Insurance companies know that doctors are acting as advocates for their patients, and their letters contain a lot of opinion. What the insurance company wants to see is **objective medical evidence** – progress notes, medication logs, labs, x-rays, imaging, other tests. I can't stress this enough. If an insurance company doctor disagrees with your doctor, the insurance company doctor's opinion will prevail. The way to change an insurance company doctor's mind is to provide **objective medical evidence** to back up your position.

If you are appealing in a case in which the insurance company thinks a treatment is experimental or investigational, you will need more than your medical records; you also will need medical journal articles. You can find articles, or at least abstracts (summaries) of articles, on the internet using one of the following research tools:

- <http://www.pubmed.gov> – the National Institutes of Health
- <http://scholar.google.com/>
- <http://www.medscape.com/medscapetoday>
- <http://www.freefullpdf.com/>

Those are the research tools I use, but I'm sure there are others. You want to find published studies that show that the prescribed treatment has been tried and tested, and is safe and effective. You should provide copies of any such materials along with your medical records and a cover letter summarizing everything. That is your best chance at success.

Here is an outline of a typical appeal letter:

- Patient's Name (and name of insured if not the patient);
- Patient's Insurance ID number, Social Security number and date of birth;
- The patient's diagnosis, including **objective** support for the diagnosis (weight loss, recent test results, endoscopy reports with pathology, etc.);
- What treatments have been tried over what period of time (go back to the date of diagnosis and describe all that has been tried and failed);
- If allegedly "experimental/investigational," summary of the medical literature, preferably including copies of the literature (both summary and copies of literature are enclosed);
- Why you believe this therapy or service is clinically indicated for you at this time.

Throughout the letter, you should cite to medical records by doctor and date, and medical journal articles by author, title, name of journal, and date of publication.

You should tailor your response to the insurer's reasoning and/or file. Here are a few examples:

- \* If you request a copy of the file and finds that the insurer did not have copies of the most recent objective medical evidence, you should emphasize that evidence in your appeal letter.
- \* If it appears that the insurer ignored some of the scientific evidence, you should summarize and attach copies of the articles they did not consider.
- \* If the policy language creates an exception for treatment of life-threatening illness, you should point that out.

Under health reform, unless you are in a grandfathered plan, you now have an additional step after the insurance company internal appeal, and this is called an **external appeal**. Most states operate external appeals for individual plans and group plans that are "fully-funded" rather than "self-funded." (See section ii, below, for an explanation of "self-funded" plans). State external appeals must meet certain minimum standards in order to comply with federal law. By 2014, all states have to meet 16 minimum consumer protections; until then, there are 13 somewhat relaxed consumer protections. For example, by 2014, states must allow 120 days to file an external appeal; but until then, states can allow only 60 days. If you read the instructions carefully and follow the rules, you should be fine. But if you have questions, every state now has a Consumer Assistance Program (CAP) that you can call and get free assistance with insurance appeals, including external appeals. You can find your state's CAP here: <http://www.healthcare.gov/law/provisions/cap/>.

Insurers in states that do not have federally approved external appeal processes that meet even the 13 relaxed consumer protections will be allowed to choose one of two options: they may direct you to an external appeal process operated by the federal Office of Policy and Management, which will be the same as the federal employee health insurance process; or they may contract directly with an Independent Review Organization (IRO) (actually, they must contract with at least two by January 2012 and at least three by July 1, 2012), which will review your appeal.

Under health reform, **self-funded plans also must offer external appeals**. For private, self-funded plans, there are two options. They can, if they and the state are willing, use a state external appeal process. In the alternative, they can contract directly with IROs and conduct their own external appeals. You can bet that they will choose the second alternative since they will be able to choose the IROs they contract with. They must have contracts in place with two IROs by January 1, 2012 and three IROs by July 1, 2012. Letting self-funded plans choose their own IROs may be like having the fox guard the henhouse, but still, some external review is better than none.

For self-funded nonfederal government plans, the external review process offers two alternatives: first, the Office of Policy and Management already operates an external review process for the federal employee health insurance plan; or, in the alternative, plans can contract with IROs on their own, just like the private self-funded plans, with all of the concerns about whether those IROs really will be independent of the plans.

Internal appeals and state external appeals must allow you to externally appeal any denial, reduction, or termination of, or failure to provide or make a payment (in whole or in part) for a benefit for pretty much any reason, including medical necessity, experimental/investigational denials, and rescissions (retroactive policy cancellations). However, under federal external appeals (states without approved processes, and private and nonfederal governmental self-funded plans), you can only appeal decisions requiring the exercise of medical judgment, at least until January 1, 2014. We know that the exercise of medical judgment will be present in any decision involving medical necessity, whether something is experimental or investigational, appropriateness, health care setting, level of care, and effectiveness. But what about coding errors? What about whether a procedure required prior authorization? The external reviewer makes the decision about whether a decision involved the exercise of medical judgment. So far, I am seeing reviewers reject appeals involving express policy exclusions, which troubles me. We'll be keeping an eye on this and reporting to the federal agencies before they produce their final regulations on appeals.

Regardless of the type of external appeal you have, your case will be given to an Independent Review Organization (IRO) which will review everything you and your insurer provide and will make an unbiased decision. IROs can overturn insurer's denials and their decisions are binding. In the hardest cases, your best shot will be an external appeal, but you have to exhaust your internal appeals first. (See section ii, below, for external appeals in self-funded plans).

If you get to the external appeal step, you should seriously consider retaining a lawyer to present your case in as professional a way as possible. If you cannot afford an attorney, you can do it yourself, but be prepared and organized. You should compile all of your medical records, a letter(s) from your doctor(s), and even a diary or other record of your symptoms. These external appeals, on the whole, are informal, but you should be prepared to present your argument in an organized fashion. Some external appeals are submitted entirely in writing, while others include a right to a hearing. At every step, make sure that you are submitting all of your medical records. Simply writing a letter explaining why you think you need the treatment in question is not enough.

In both internal and external appeals, your argument should always be "this is medically necessary." That is the standard, medical necessity. If you and/or your doctor can explain why the treatment in question is medically necessary, you should win your appeal.

The definition of "medical necessity" varies from insurer to insurer, and sometimes from state to state. Among the documents you should obtain from your insurance company is a copy of the policy language. Note that, for group plans, including those sponsored by an employer, at



best, the insurer sends one copy of the actual policy to the group plan administrator. You don't need the entire policy; what you need is a certificate of coverage or summary plan description.

Once you exhaust your rights to appeal, you then can go to court. Quite honestly, when I write on behalf of patients, I rarely lose, not because I am doing anything special, but because I am a lawyer and insurance companies don't want to litigate. It frustrates me that I get better results when I write on law firm letterhead than when I write a letter on plain paper – patients should be respected regardless of the paper they write on. However, the reality is that it makes a difference. The key, though, is finding a lawyer willing to handle the insurance company appeal *only*, as opposed to someone who wants to litigate. A simple health insurance claim may be able to be resolved with not much more than a letter and a phone call or two; a more complex one may involve review of medical records and such. In any event, a health insurance appeal can be relatively inexpensive compared with going to court. It's always worth a try.

## ii. Self-funded Plans

The next few paragraphs are going to be maddeningly complicated. I apologize up front – there is no avoiding it. I will do my best to make it as clear as possible. However, even lawyers have trouble with some of this. Still, it's important for you to know, so if it takes reading it twice, do so.

All employer-based group insurance (whether it be health, disability, or other insurance) is governed, at least in part, by a federal law known as ERISA.<sup>1</sup> Some plans, called self-funded plans, are governed **solely** by ERISA, so state laws, such as laws creating external appeals, do not apply. Self-funded plans look like regular insurance plans, but instead of paying an insurance premium in exchange for which the insurance company pays for health care, the employer pays a third party – usually an insurance company – to administer the health insurance plan, while the employer pays for the actual health care. Self-funded plans are most typically offered by large employers. Remember – state law does not apply to a self-funded plan, whereas both state law and ERISA apply to regular insurance plans (called “fully-funded” plans).

In addition to private self-funded plans, there are nonfederal governmental plans – school districts, utility companies, water districts – that also are self-funded. However, these plans are NOT governed by ERISA. They also aren't governed by state law. If they are regulated at all, it is by the United States Department of Health and Human Services.

If your group health insurance is governed by ERISA, you have very helpful procedural rights, but very limited substantive rights.

As far as substantive rights, ERISA requires that you file suit in federal court, and that you meet a very difficult burden of proof. Insurance companies are entitled to “remove” a case filed in state court that is governed by a federal statute like ERISA, forcing the case into federal

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<sup>1</sup> The Employee Income Retirement Security Act, 29 U.S.C. § 1001 *et seq.* ERISA ONLY applies to benefit plans you get through employment. If you have insurance through an association or other group that is not sponsored by an employer, ERISA does not govern your plan.

court. ERISA is very complicated, and if you are in federal court in a case governed by ERISA, you have to show that the group insurance plan administrator acted “arbitrarily and capriciously” in order to prevail. The “arbitrary and capricious” standard is a much higher burden of proof than the one used in most civil cases, the “preponderance of the evidence” standard. In other words, once you are in federal court under ERISA, your chances of winning are slim.

However, ERISA exempts from its reach issues related to the states’ power to regulate insurers (except with respect to self-funded plans, which are governed exclusively by ERISA). Thus, there are certain state laws that apply to even ERISA-covered group health insurance plans.

If you file in state court and your case is “removed” to federal court because it is governed by ERISA, but you have rights under state law, you will have an opportunity to argue that your case should be “remanded” to the state court because your case involves the state’s power to regulate insurance and, thus, is exempt under ERISA. However, according to the Supreme Court, any case involving the question of whether a particular treatment or service is covered under an employment-based group health insurance plan is governed by ERISA, making it difficult to win when the question involved substantive rights.<sup>2</sup>

If it gave you a headache to read the last few paragraphs, you have some idea of how complex, and how expensive, this sort of litigation can be. Thus, my strong belief is that internal and external appeals are where the most cases should be fought and can be won with self-funded plans.

However, the great benefit of ERISA is in the area of procedural rights. ERISA requires “full and fair review” by ERISA plan administrators.<sup>3</sup> The statute sets out the following duties for plan administrators, most of which remain in effect after health reform, who must:

- provide adequate notice in writing to any participant or beneficiary whose claim for benefits under the plan has been denied, setting forth the specific reasons for such denial, written in a manner calculated to be understood by the participant, and
- afford a reasonable opportunity to any participant whose claim for benefits has been denied for a **full and fair review** by the appropriate named fiduciary of the decision denying the claim.

In addition, the Department of Labor has written regulations that further clarify the nature and scope of full and fair review. An insurance company’s denial letter must contain the following:

- (1) The specific reason or reasons for the denial;

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<sup>2</sup> *Aetna v. Davila*, 124 S.Ct. 2488 (June 21, 2004), holds that ERISA pre-empts any state court suits against insurers for the consequences of refusing to provide coverage.

<sup>3</sup> 29 U.S.C. § 1133.

- (2) Specific reference to pertinent plan provisions on which the denial is based;
- (3) A description of any additional material or information necessary for the claimant to perfect the claim and an explanation of why such material or information is necessary; and
- (4) Appropriate information as to the steps to be taken if the participant or beneficiary wishes to submit his or her claim for review.<sup>4</sup>

There is a tremendous amount of litigation over what constitutes ERISA “full and fair review.” What is absolutely certain is that “full and fair review” means the following:

- You must be given reasons why your claim is denied. Those reasons can’t be so general that they tell you nothing. For example, they can’t say “the item is not medically necessary to treat the patient’s clinical condition” because that would fit just about any denial. Most insurance companies break this rule hundreds of times a day.
- You must be given access to and copies of your file.
- If the insurance company had some information that they chose not to consider, they have to tell you that, and provide you copies of any documents that would have supported your position.

These are the basics of “full and fair review.” Under health reform, most of these provisions have been incorporated into the rules for fully-funded plans, too, so denial letters will become pretty similar regardless of whether you are in a fully-funded plan or a self-funded plan.

In my experience, the people you can speak to by phone don’t have any idea that these rights exist. In particular, when I write an insurance company taking them up on their offer to send me a copy of the entire file, and I don’t get a response, I then start calling. Time after time, I get people on the telephone who don’t know that this language is in the denial letter, and who don’t know that this is an enforceable legal right. I have had people at insurance companies tell me that they would have to review the file and decide what I was allowed to have when the law states quite clearly that I am entitled to everything.

The procedural rights created by ERISA are wonderful when they are enforceable. However, it takes great persistence to get the insurance companies to comply and provide you with everything to which you are entitled. Still, you should assert your rights in writing, follow up by telephone taking careful notes, and include in your appeal letters any procedural violations that you believe have occurred.

If you do not raise these issues with the insurance company, you may not be able to do so for the first time in court. So at the very least, make it clear, in writing, that you have requested documents and/or more explicit reasons for the denial of coverage. Say this at every level of appeal. This is called preserving the issue.

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<sup>4</sup> 29 C.F.R. § 2560.503-1(f).

Quite a few courts have granted benefits because the insurance company did not perform a “full and fair review.” Whereas you may not win an appeal of a noncoverage decision because you can’t meet the “arbitrary and capricious” standard, you may well win if you have maintained documentation of your requests for copies of the file and/or reasons for denial sufficient to make out a claim of denial of “full and fair review.”

### iii. Off-Label Uses of Pharmaceuticals

Insurers often deny coverage of new and expensive medications on the ground that they were being prescribed for a use other than that for which the FDA approved the drug. In other words, coverage of a pain medication like Actiq, which is FDA approved only for cancer pain, would be denied if it was being prescribed to treat any other type of pain.

When a drug is being prescribed for a use other than what it was FDA approved for, this is called an off-label use.

Both Medicare Part D (the Medicare drug benefit) and private insurance companies are denying coverage for off-label uses, or at least some off-label uses. There are many medications that are prescribed off-label every day, and which are covered. In my case, most of the medications I take for my Crohn’s disease are not FDA approved for use in treating Crohn’s disease. Yet, insurance covers them routinely. So why do they cover some off-label uses and not others?

Part of the explanation is that, in addition to FDA labeling, Medicare and private insurers rely on certain “compendia” that establish what drugs can be used for what things. Some insurers also rely on papers compiled by consultants, who take a very narrow view of what uses are appropriate.

But one thing appears to me to be clear: The off-label uses that are not covered most often are those involving new and expensive drugs. For example, Actiq – which is just another form of fentanyl, which is a widely used pain medication – costs well over \$1,000 for a one-month supply.

The denial of coverage for off-label uses is nearly impossible to overcome. As you can see in letters E and F in Appendix C, even though the FDA itself has encouraged doctors to prescribe for off-label uses, Advocacy for Patients has taken denials of coverage all the way up the line to external appeals to State Insurance Departments and as far as we can go in Medicare, and there is no easy way to win this fight. The Medicare Rights Center won a lawsuit in federal court in New York challenging the exclusion of off-label uses, but that ruling is on appeal.

Indeed, sometimes it’s hard to determine what provision in your policy the insurer hangs its hat on in the context of off-label uses, i.e., are these medical necessity appeals or denials of coverage of “experimental, investigational, or unproven” treatments? I tend to think it’s the latter, which means that you have to submit, in addition to medical records, scientific evidence supporting the off-label use. Based on our experience, it is not enough to submit medical journal



articles that show that some off-label uses are supported; you have to show that there is support for the precise off-label use you are arguing for. For example, when we appeal a denial of coverage of Actiq, the pain medication, we present copies of articles showing that Actiq is being used for many off-label uses, including migraines and sickle cell disease. However, in the absence of a successful study showing that Actiq can be used successfully in treating your particular condition, these articles have not, in our experience, gotten us the result we are looking for.

We even have seen this rationale applied to justify noncoverage of a larger dosage of an FDA approved medication. Recently, we got an email from a patient saying that her doctor had prescribed a high dosage of an anti-depressant and she did not understand why her insurance wasn't willing to pay for it. On a hunch, we looked at the FDA labeling, which says "there is no clinical evidence to support the use of a dosage higher than 60 mg. per day." That was the answer; it was an off-label use. That's why a letter from her doctor did not do any good. In the absence of medical journal articles showing that, in fact, there is evidence that a higher dosage would be appropriate in certain circumstances, there was no way around the denial of coverage.

In the end, this is perhaps the hardest type of insurance appeal, although those of you who know me know I rarely give up! On this issue, I think the change is going to have to happen in Medicare, from where it might trickle down to the commercial insurers. In any event, know that, if you are faced with an off-label use problem, you are facing one of the toughest fights there is in the health insurance world. Whether you handle it yourself or you ask Advocacy for Patients for help, this is a very steep uphill climb.

#### iv. Final note.

My sense of the process is that insurance companies expect a certain percentage of denials not to be challenged at all, and smaller and smaller percentages to appeal at each successive step in the appeal process. The persistent definitely have an advantage solely because they persist. Of course, that's harder for those of us who are sicker. But unfortunately, the system rewards the patients who advocate for themselves. To assist you in this regard, you will find a number of sample appeal letters dealing with both substantive rights and procedural rights in Appendix C.

### **C. Prescription Drug Patient Assistance Programs**

Believe it or not, just about every pharmaceutical company in the country has a patient assistance or compassionate care program through which they provide free medications to patients who meet their criteria. You have to go through an application process, including proving that you don't have insurance or can't get the drug you need through your insurance, and also showing that you can't afford to buy the drug on your own. Don't assume that your income is too high; it may not be.

I am listing a number of websites below. I tend to use [www.needymeds.com](http://www.needymeds.com) the most. I find that their list of drugs is very complete, and it's a very easy website to navigate. However, all are of tremendous value. Try a few and see which one(s) you find most helpful. In addition,

there may be others – in fact, some of the resources I list here are pretty new, including one put up by the pharmaceutical companies themselves.

- [www.needymeds.com](http://www.needymeds.com) - again, I find this site particularly easy to navigate.
- [www.together-rx.com](http://www.together-rx.com) - this is a pharmacy discount plan. If you don't qualify for free meds, you might try this discount program (and others that I'm sure are being created on a regular basis). Make sure to check to see if your meds are covered before you sign up.
- [www.pparx.org](http://www.pparx.org) - this is the website established by the pharmaceutical companies. If you don't have a computer, their toll-free number is 1-800-477-2669.
- [www.rxhope.com](http://www.rxhope.com) - this site says that it provides information on government and corporate sponsored patient assistance programs for over 1000 medications. I have not used it much, but I include it here since it might be the one you will like the best.
- [www.cdfund.org](http://www.cdfund.org) – the Chronic Disease Fund, which says it helps people with chronic illnesses afford their medications. If you don't have a computer, you can reach them at (877) 968-7233.

When you sit down at your computer to try to find your medications on one or more of these websites, try to have both the generic and brand name of the medication you need. There may be more than one program for the same drug but using a different name. You may find several manufacturers for the same generic.

Not all generics are the same. In fact, not all generics are really the same as the brand-name drug. Ask your doctor if the generic is the same. I take one medication that is markedly different from the generic and there is a reason my doctor wants me to be taking the specific brand. Don't assume your doctor would have told you about this; ASK.

One resource we all under-utilize is our pharmacist. Not every pharmacist in every big chain store is going to take a personal interest in your care, but if you are lucky, you will find one of many exceptional pharmacists who do care, and who do want to help. They won't mind helping you find the least expensive ways to get your medications. Most pharmacists can and will help you determine if a brand your doctor ordered is identical to the generic. In addition, they will know about prescription drug discount plans. At times in my life when I have had a great pharmacist, he or she has become as important a part of my medical "team" as my doctors. A good pharmacist knows how to work around hard and fast insurance company rules to get you what you need.

#### **D. Co-Pay Assistance**

Finally, if you need expensive testing or treatment (such as Remicade) and your insurance covers only 80% of costs, you may have problems paying your 20% co-pays. There are several co-pay assistance programs of which I am aware.

The first is run by the Patient Advocate Foundation and you can find all the information about the program at [www.copays.org](http://www.copays.org), or you can call toll-free at 1-866-512-3861. The second is run by the Patient Access Network Foundation, which can be reached at [www.panfoundation.org/](http://www.panfoundation.org/) or 1-866-316-7263. The Chronic Disease Fund also helps with co-pays. [www.cdfund.org](http://www.cdfund.org) or 1-877-968-7233. Two newer programs are The Healthwell Foundation at <http://healthwellfoundation.org/> or 800-675-8416; and The Assistance Fund, <http://theassistancefund.org/> or 877-245-4412.

These programs relate only to certain treatments for certain diseases, so see if yours is on the list. All three programs will ask you for financial information to determine your eligibility. In addition, none of these programs covers every procedure or treatment for every disease, so call and ask to find out if there is co-pay relief available to you. Finally, these programs do run out of funds at times, so these are not guarantees.

In addition, there is a program called Patient Services, Inc. PSI provides assistance to people who live with certain chronic illnesses or conditions locate suitable health insurance coverage and access ways to satisfy expensive co-payments. PSI provides assistance with the cost of health insurance premiums associated with COBRAs, State High Risk Pools, Open enrollment, guaranteed issue policies, HIPAA conversion policies; and prescriptions co-payments associated with private insurance as well as with Medicare Parts B and D. Again, though, they only work with a finite number of diseases. For more information, go here <http://www.uneedpsi.org/CMS400Min/index.aspx> or call 1-800-366-7741.

#### **E. Other Financial Assistance for Health Care-Related Debt**

The hardest requests for assistance I get are the ones in which people are asking for money to help pay medical bills or other debt that has amassed due to illness. The short answer here is there is none, or if there is, I haven't found it. I've already talked a little about charity care, and later on in this *Handbook*, I will talk a little about emergency assistance, and will direct you to some resources there. In addition, there's a small organization called Modest Needs that provides small, one-time grants of financial assistance. [www.modestneeds.org/](http://www.modestneeds.org/). But unfortunately, no wealthy person I know of has set up a fund to be used to help pay medical bills, or to help with other expenses when medical bills get out of control.

Financial assistance is the hardest thing to find in terms of resources. Do your best to set up payment plans with creditors and then stick with those plans. If worst comes to worst, you may have to consider bankruptcy as a final option.

But the best advice I can give you is to try to stay on top of things and deal with them before they get to a collection agency. I know that is impossible some of the time. If you are very ill and going through lengthy hospitalizations and so on, you may need to enlist the assistance of a family member to help you notify creditors that you are ill and see what they are willing to do until you are back on your feet.

And use any remissions you have to try to save money. I keep six months of savings in the bank at all times in case I become unable to work. It was hard to save up that much, and it's been hard not to use it at times, but it gives me great peace of mind to know that it's there.

I wish I had better answers on this subject. Perhaps someday Oprah Winfrey, Bill Gates, Bill Clinton, and others will create a pool of money to help people in the midst of a health care crisis. (How about writing them letters explaining the need for this sort of fund?) Until that happens, I think we're on our own, and just have to do the best we can.

## **VI. Private Disability Insurance**

This Section relates to a number of issues relating to private disability insurance. First, patients need to understand how to obtain disability insurance. Second, it is important to know how to file an initial claim of disability. Third, patients, doctors and lawyers should know how to appeal an adverse decision.

### **A. Choosing the Best Disability Insurance**

If you are fortunate enough to be covered by private disability insurance (short- or long-term), you are one of the lucky ones. The only way that I know of that a chronically ill patient can get disability insurance is through an employer-based group plan.

If you have options about the choice of disability insurance, or if you are appealing a denial of coverage, the most crucial thing to look at is the definition of "disability." Some policies pay benefits if you are unable to perform the functions of **any** job ("any occupation"), and others pay benefits if you are unable to perform the functions of the **particular job** you are in when you buy the insurance ("own occupation"). If you have a choice, you want the latter kind, the kind that pays if you cannot perform the functions of the particular job you are in. That means that if I can no longer practice law, for example, I get paid even if I might be able to do something physically easier, like answering phones or doing word processing. The burden of proving that you are disabled is much easier under this type of policy.

More and more, I am seeing a hybrid of these two types of disability policies. Under these hybrids, you are disabled if you cannot perform your particular job for some period of time (typically one or two years), after which you are disabled only if you cannot perform any job. Some policies limit benefits for a mental health disability to two years, but pay unlimited benefits for a physical disability. Be careful when buying a policy to make sure you understand exactly what you are buying.

I have been working with a patient for many months who elected the least expensive disability insurance when she started her job because she wasn't being paid much and felt that she could not afford the more expensive plan. That was when she was young and healthy. Many years and three bouts of cancer later, she wishes she had that choice to make over again.

You should be aware that most private long-term disability insurance is written so as to require you to apply for Social Security Disability ("SSDI") if you are found to be disabled.



Social Security benefits will then be offset against your long-term disability insurance benefits. If you go through the SSDI application process and are found to be disabled, you will owe the private disability carrier the lump sum retroactive payment that you will receive from Social Security, and your disability insurance will pay you only that amount that exceeds the SSDI benefit.

For example, let's say you are found to be disabled by your commercial disability insurance carrier. They pay you \$1,500.00 per month. You then apply for SSDI and are granted, retroactive to the date of your application. You will get a lump sum in the amount of your SSDI benefit retroactive to the date of onset of your disability. To continue with our hypothetical, let's say that your SSDI benefit is \$1,200.00 and that your disability onset date (after the 6 month waiting period – see below for detailed information about SSDI) was six months before you got a decision, so you get a check for six months' worth of SSDI benefits, or \$7,200.00. Since your private disability insurance is allowed an offset against your SSDI benefit, and since you have already been paid by your disability insurer for the same six months that SSDI just paid you in the form of a lump sum, the only way to preclude you from being paid twice for that same six months is if you are required to turn that lump sum SSDI check over to your private insurer. After that, because of the right of offset, you will receive \$1,200.00 in SSDI benefits and only \$300.00 from the private disability insurer, or a total of \$1,500.00, the amount of your private insurance benefit.

Do not try to hold onto that lump sum SSDI check you get. The private insurer has a right to sue you for it. At the very least, they will apply the \$300.00 per month benefit that you are supposed to get against the debt you owe them. Holding onto the lump sum will get you nothing in the long run.

As a matter of law, the scenario I describe above is absolutely legal, regardless of whether you think it is fair. My advice to you is, if you get a lump sum SSDI check, do not spend a dime of it until you determine whether your disability insurance carrier has a right of offset.

In sum, if you have a chronic illness, it is nearly impossible to find disability insurance as an individual. A broker once came to me and said he was sure he could find me disability insurance that would cover my Crohn's disease. I said I didn't believe it and I was unprepared to force my doctors to turn over copies of my HUGE medical charts for no good reason. So we submitted my six operative reports to the insurance company, which said sure, they would cover my Crohn's. Encouraged, I decided to go ahead. After they got the rest of my medical records, they offered me a policy that excluded anything related to my digestive track. I was not amused, and this is the norm. It is nearly impossible to find disability insurance outside of an employer-based group that would cover your chronic illness.

## **B. Filing a Claim for Disability Insurance Coverage**

If you become disabled, you must file a claim. Again, start with your policy's definition of "disability." What you will have to show is that you meet that definition. If your policy defines "disability" to include the inability to perform any job, you will want to address all of the

functions you are unable to perform, and not just those involved in your particular line of work. Your argument should be tailored to the policy definition of “disability.” If your policy defines “disability” to include the inability to perform only the job you were in when you became disabled, you will want to get a copy of your job description and stress your inability to perform the functions listed in the job description.

The insurance company will ask your doctor(s) to fill out forms, and may ask for your medical records. But be advised that it is up to you to prove that you are disabled. Do not count on your insurance company or your doctor to be your advocate. You must make your case.

Although the standard for SSDI is different from the standard for private disability insurance, you may wish to use it as a guide. *See* Appendix F for a table of contents of the Social Security listing of impairments, known as the “Blue Book.” If you can show an insurer that you meet the SSDI criteria, you can make a strong argument that the private insurance standard should not be more difficult to meet because, under SSDI, the claimant must show that he cannot perform his former job, and the SSA then has an opportunity to show that there are other jobs he could perform. Thus, even if your insurance policy says you have to show that you cannot perform *any* job, the SSDI criteria can be used as a guideline.

You should collect your medical records and submit them to the insurer, and you should obtain letters from your doctor(s) in support of your claim. This is absolutely crucial. In some jurisdictions, and with most insurers, the treating physician’s word carries great weight unless it is contradicted by substantial evidence. (*See, e.g.,* Appendix I). It should be given substantial weight by a private disability insurer. In addition, you should keep a record of how you feel each day, what you can and can’t do, how many times you go to the bathroom or vomit – every detail of your daily routine matters. *See* the disability appeal sample letters in Appendix D, demonstrating the level of detail that is advisable.

### **C. Appealing an Adverse Decision**

I trust that, when you finally decide to file a claim for disability, it will be because you cannot work. Contrary to the beliefs of many insurers, most patients do not want to be on disability; they have to be. That means it will be harder than ever to muster the strength to advocate for yourself. But you must, unless you can afford to hire a lawyer.

Even with a lawyer, continue to be your own advocate. As with health insurance appeals, lawyers may be prone to litigate. However, exhausting all internal appeals is necessary before you are allowed to litigate, and it’s far less expensive. Make sure you have a lawyer who is willing to put on a full-court press at the internal appeal stage, in an attempt to avoid litigation. In addition, see the discussion in Section V.B.ii about ERISA. That federal law will apply to most issues relating to employer-based group disability policies in the same way that it applies to employer-based group health insurance policies, putting you in federal court and making the patient’s standard of proof – the “arbitrary and capricious” standard – far more difficult to meet. This makes internal appeals the preferable route, in my view.

Many lawyers take disability insurance appeals on a contingent basis. They will ask you to sign over one-third of whatever you get. My personal opinion is that this is too high if there is a good possibility of success *without* litigation (although if your case proceeds to litigation, one-third probably is fair). In my opinion and my practice (before I started Advocacy for Patients, which does disability insurance appeals for free), a flat amount rather than a percentage is generally more appropriate for cases resolved prior to litigation. It may be difficult to find a lawyer to accept less than one-third on a contingent basis, though.<sup>5</sup>

Disability appeals occur in two circumstances: one, your initial claim of disability can be denied; and two, your ongoing disability benefits can be discontinued on the basis that the insurer thinks you no longer are disabled.<sup>6</sup> In either case, you are entitled to an appeal.

There are at least two ways you can “win” either type of appeal. First, you can convince the insurer that you are disabled, and that they were wrong to deny your claim. If you do that, you will be entitled to benefits retroactive to the date of the claim (or if you were on disability and it was cut off, retroactive to the date of the cut-off), as well as monthly benefits going forward. In the alternative, if you have a repetitive problem with an insurer and want it to end, you may invite the insurer to buy out your policy. In this case, you can get a lump sum from the insurer that represents some portion of what you could be expected to receive for the duration of your disability. Be advised that, if you follow this route, the policy will be terminated. However, for enough money, that may be worth it to you. I negotiated one buy-out for \$400,000 – a very substantial payment for my client, eliminating the monthly reporting which, for her, was so stressful that it was compromising her health.

Disability appeals require more intensive analysis of your medical records than health insurance appeals because the stakes are much higher, both for you and for the insurance company. Although an insurance company will retain the right to revisit your case periodically, once you win an appeal, the company knows it will be paying you monthly benefits for some period of time. Unlike a health insurance appeal, it is nearly impossible to appeal to a disability insurer’s sense of compassion because of the amount of money involved. Thus, it is rarely as simple as writing a single letter on your own.

The most important thing is to stress **objective indications** of disability. Although you must be clear and detailed about how you feel and what your life is like, you will need test results and physician notes to prove your case. It is critical that you not assume the insurer has everything it should have, or that it fully understands and appreciates it. In your appeal letter, go through your medical chart and demonstrate, by reference to test results and physician notes, that there is objective evidence that you are disabled. Endoscopic and other biopsy results, blood test results, CT scans, x-rays and MRIs all are objective evidence to show not only that you are sick, but more importantly, that you are not exaggerating. Your credibility will be tested; without

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<sup>5</sup> A contingent case is one in which your lawyer does not get paid unless you win.

<sup>6</sup> This can happen with disability retirement plans, too. This section applies to appeals from denials or discontinuations of disability retirement benefits, as well as disability insurance benefits.

getting defensive, you must demonstrate why you should be believed. The best evidence that your subjective complaints of disability are credible will be this type of objective evidence.

Certain illnesses do not lend themselves well to this sort of objective analysis. Disability appeals involving headaches, chronic pain, fibromyalgia, chronic fatigue syndrome – these are the hardest to win because there is not always an objective measure to prove that you actually have the disease or condition. We have added a sample disability appeal involving chronic fatigue syndrome in Appendix D (letter B). You will note that we used every objective measure that we could find in the file.

Don't forget that you have to show not that you are sick, but that you are unable to work. Unless you meet the definition of "disability" under your policy, being sick is not enough. If you have one of the policies that requires that you be unable to perform any job, you need to explain why you can't even perform a light-duty sedentary job, such as answering telephones. Keep your focus on that standard, that definition of disability. No matter how sick you are, if you don't prove that you are disabled as defined in your policy, you will not be found eligible.

Finally, once again, if you lose your internal insurance company appeals, you can go to court. However, the Supreme Court has ruled that the deference typically afforded the opinion of the treating physician in the context of Social Security Disability benefits (*see below* Section VII and Appendix I, Section 2), does not apply under ERISA.<sup>7</sup> This gives administrators of ERISA-governed disability determinations even more discretion to make disability determinations. In other words, without getting overly technical, it's simply very difficult to win in court, which is all the more reason to take the insurance company appeals seriously.

#### **D. Independent Medical Examinations**

A disability insurer may have an Independent Medical Examination (IME) performed before denying your claim. That means you are examined by a doctor hired by the disability insurance company to review your case. Make no mistake – these doctors work for the insurance company. The worst of them are looking to find a way to find that you are not disabled, although some are fairer than others.

Your conduct during the IME is very important. Do not try to exaggerate, or they will immediately question your credibility. On the other hand, do not leave out details. The doctor conducting the IME should have reviewed your entire file, but will not know what it's like to be in your shoes. Make sure you discuss the effects of your illness not only on work, but also on your home and family life. If you no longer can clean your house or drive or travel or care for your children, you should inform the Examiner accordingly. If you are depressed as a result of your illness, that may constitute a separate disability, and you should mention it on your claim form, as well as in your IME. Do not worry about sounding like you complain too much; it is your job to make sure the Examiner gets a sense of what your day-to-day existence is like.

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<sup>7</sup> *Black & Decker v. Nord*, 538 U.S. 822 (2003).



If you get a good result from the IME – which does happen occasionally – it is likely (although not certain) that you will win. The insurer will have difficulty denying your claim if its own doctor says you are disabled. So the IME is terribly important.

On the other hand, if the IME report says you are not disabled, that doesn't necessarily mean you lose. However, you need to get a copy of the IME report (which will be provided to you by the insurer), and you need to pick it apart, line by line. You need to cite to your medical records and to your treating physicians' letters and reports to explain what the IME missed and why it was important.

In one example, I represented a woman who had claimed two disabilities: carpal tunnel to her hands and severe depression. The insurance company had her undergo two IMEs. One IME doctor had a website bragging about results he gets for insurance companies, allowing me to argue that his report was unreliable due to bias. The other IME doctor had made a couple of passing comments that actually supported our claim of disability, although you had to read very carefully to pick them up since his overall conclusion was that my client was not disabled. But the most important point is that the insurer completely missed the carpal tunnel disability, and only did IMEs on her mental health disability. I cited to every single document in the file that pertained to the carpal tunnel disability to show that the insurer was on notice that she claimed two separate disabilities. My appeal letter was 10 single-spaced pages, going over the file bit by bit. It took a fair amount of time, but it was very successful for the patient. (See Appendix D, Sample Letter A, edited to eliminate some of the repetitious detail).

### **E. Final Thoughts on Disability Insurance**

Although I don't have statistics on the number of disability insurance appeals that are successful, I can tell you that I very rarely lose a disability appeal. My experience tells me that, if you take the appeal step very seriously, you may well get a positive result without needing to litigate. Litigation of disability appeals suffers from the same complexity as health insurance appeals. If your disability insurance is employer-based, the federal ERISA law governs, and you are subject to a very high standard of proof. So take the internal appeal step very seriously; in my experience, it is by far your best chance of success.

## **VII. Social Security Disability**

Many patients must face a time in the course of their disease when they cannot get up and go to work every day. Fortunately, I have a job that can be done largely from home, so although I have had to sweat out some lean months, I never have had to worry about being fired or going on disability.<sup>8</sup> The decision itself is very tough on people; they don't want to give in and admit that they can't work. What I focus on here is what happens once that decision is made.

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<sup>8</sup> See Section VIII of this Handbook for additional employment-related information.

## **A. Resources**

Normally, I would list resources at the back of a section. However, here, because access to answers is so critical, I start with where, in addition to this *Handbook*, you can and should look.

The best resource there is for information about the Social Security Disability application and decision process is the Social Security Administration (SSA). The SSA website is [www.ssa.gov](http://www.ssa.gov). If you don't go there to read everything there is on the process before you apply, you are doing yourself a huge disservice. Really, everything you need to know is there. In fact, SSA has made some very useful improvements to their website. It is user-friendly and very informative.

There are a number of Appendices to this *Handbook* that will be helpful, too. First, the table of contents of the "Blue Book," which contains all of the criteria for all types of disorders, can be found in Appendix F. If you are applying for SSDI, these are the criteria you need to meet to be considered disabled. Appendix G contains materials prepared by a patient who was successful in obtaining SSDI on her initial application. Appendix H contains a sample request for reconsideration. Although both of these patients have IBD, the illustrations apply regardless of illness. These materials are included here to demonstrate the extraordinary degree of specificity and graphic detail that you will have to provide. Nothing is too private.

## **B. Access to Your Medical Records**

In addition, although this is widely unknown, you are entitled to access the medical records the Social Security Administration (SSA) collects from your health care providers. Section GN 03340.035 of the Policy Manual requires that applicants and their designated representatives be provided with their medical records as long as releasing those records to the applicant is not likely to create an adverse effect for the patient. An adverse effect exists if releasing the records would disrupt a doctor-patient relationship, interfere with the patient's medical care, or otherwise negatively affect a patient. For example, an applicant with a severe heart impairment whose doctor has noted in the file that the individual's knowing of the severity of the problem could cause medical complication should not be provided access to her medical records. If the SSA will not release the records to the applicant, the applicant may designate a representative who can receive the records. In any case, the SSA will provide a written response to your request for your medical records.

Children's records are not automatically released to the parent or guardian. Instead, a health care provider must be designated for receipt of the child's records.

## **C. Eligibility Criteria**

To qualify for SSDI, you must be disabled and either (1) under age 65; (2) disabled since childhood and a dependent of a deceased "insured" parent (a parent who meets the earning tests – see next paragraph) or a parent on SSDI; or (3) a disabled widow or widower, age 50-60, if the deceased spouse was "insured" (again, see next paragraph).

In addition to proving that you are disabled (see below), to get SSDI, you must have a sufficient number of work credits. The number of work credits needed for disability benefits depends on your age when you become disabled. Generally you need 40 credits, 20 of which were earned in the last 10 years ending with the year you become disabled. However, younger workers may qualify with fewer credits.

**Before age 24--**You may qualify if you have 6 credits earned in the 3-year period ending when your disability starts.

**Age 24 to 31--**You may qualify if you have credit for working half the time between age 21 and the time you become disabled. For example, if you become disabled at age 27, you would need credit for 3 years of work (12 credits) out of the past 6 years (between ages 21 and 27).

**Age 31 or older--**In general, you need to have the number of work credits shown in the chart below. Unless you are blind, you must have earned at least 20 of the credits in the 10 years immediately before you became disabled.

Born after 1929, Become Disabled after Age...	Number of Work Credits
31 through 42	20
44	22
46	24
48	26
50	28
52	30
54	32
56	34
58	36
60	38
62 or older	40

This is what it means to be “insured” for purposes of Social Security. If you are not “insured,” see Section VII.F, below, on Supplemental Security Income or SSI, which is available even if you are not “insured.”

One caveat: If you did not pay into the Social Security system, you are not eligible for SSDI. Some school teachers, hedge fund managers, and others do not have FICA tax withheld from their paychecks. They will not be eligible for SSDI.

SSDI is not income-based. If you are disabled and low-income, you may wish to look into Supplemental Security Income (SSI) rather than SSDI. Dependent children living in your home also may be entitled to benefits. SSDI gets you Medicare starting 2 years after you begin receiving SSDI benefits, whereas SSI gets you Medicaid right away. The standard for proving that you are “disabled” is the same under both SSDI and SSI.

You can receive SSDI and still work, although you must restrict yourself to earning less than what the SSA considers “substantial.” Each year, the SSA determines the dollar amount that meets this standard, but it is right around \$1,000 per month. In truth, though, at least at the time you apply, if you can work at all, it will be difficult to convince the SSA that you are severely disabled.

#### **D. Overview of The Disability Application Process**

Most of the patients I know who have applied for SSDI have been denied on the first try. They have moved for reconsideration, and then appealed (gone to hearing), and many have won. However, if you wish to take your case to a hearing, I **strongly** advise retaining a lawyer or non-lawyer representative to represent you. The ability to present evidence and testimony in a persuasive and organized fashion is crucial. Although the hearings are not very technical, it is best to put on a presentation rather than just answering questions. A lawyer will be best able to present your case in an orderly fashion. If you run into a lawyer who isn’t optimistic about your chances, feel free to seek a second opinion, just as you would from a doctor.

There are lawyers around the country who specialize in SSDI appeals. I am not one of them. They accept a standardized fee equal to the lesser of \$5,300 or 25% of any retroactive benefit you receive if you win<sup>9</sup>, and nothing if you lose. The National Organization of Social Security Claimants’ Representatives (NOSSCR) is the best source of attorney referrals. Their website is at [www.nosscr.org](http://www.nosscr.org). There is a particularly excellent set of FAQs on their website, as well.

To apply for SSDI, you will need the following information:

- Social Security number and proof of age;
- Names, addresses and phone numbers of doctors, hospitals, clinics and institutions where you have been treated, as well as dates of treatment;
- Names of all medications you are taking;
- Medical records – everything you can get your hands on, including lab, x-ray reports, scans, and endoscopy results;
- Summary of your employment history;
- Your most recent tax return.

The SSA is supposed to gather your medical records, but the better prepared you are, the stronger your application will be and the better your caseworker will feel about you (and your relationship with the caseworker can make a difference).

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<sup>9</sup> For example, if you apply in November 2007 and are granted benefits in June 2008 with a disability onset date of January 2006, you are eligible for benefits 6 months after the disability onset date, or starting June 2006. You would be entitled to retroactive benefits covering the period from June 2006 to June 2008. Your lawyer or non-lawyer representative will be entitled to the lesser of either \$6000 (this amount is adjusted periodically) or 25% of that retroactive benefit.



SSDI applications can be filed with a field office in person<sup>10</sup>, by telephone, or by mail. The field office will then verify the basic information, such as age, employment, and marital status. Then, most claims are processed first by state agencies known as Disability Determination Services (“DDS”). DDSs are federally funded, but administered by the states. DDS will collect your medical records and gather other information about you. DDS may speak with your doctor(s) and request additional information, or may ask you to see a consulting physician. DDS actually makes the initial disability determination through a two-person team including the case worker and a physician or mental health professional (psychiatrist, psychologist, social worker).

Once you are determined to be disabled, you will remain on SSDI unless you earn too much or your health improves. The SSA will do periodic reviews of your condition to determine if you remain disabled. When you are granted benefits, your condition will be characterized based on whether improvement is expected. If improvement is expected, your case will be reviewed in about 18 months from when benefits commence; if improvement is possible, review will occur in about 3 years; and if improvement is not expected, review should not occur for 7 years. With a chronic illness, expect reviews at either 18 months or 3 years.<sup>11</sup>

You can apply for SSDI as soon as you become disabled, but you will not receive benefits until 6 months after disability onset. In other words, your first check will be for the sixth full month after the disability onset date. You don’t have to exhaust your savings; you may be on private disability insurance, on sick leave, or on worker’s compensation. However, realistically, most people will exhaust their savings waiting for a hearing and/or decision. Plan in advance; expect at least a year without income when you apply.

If you are denied on the first try, you then apply for reconsideration.<sup>12</sup>

The next step if your claim is denied is to request a hearing before an Administrative Law Judge. I strongly advise you to have an attorney or other representative at this hearing; there are aspects of putting on a case that take some knowledge and experience, such as how to cross-examine a vocational expert that SSA has testify against you. You may introduce new evidence at the hearing and present your own testimony, as well.

If you lose at hearing, your next step is to the Appeals Council.

Finally, if the Appeals Council rules against you, your next step is into the court system. The court will decide whether to overrule the SSA’s decision by granting benefits, or, more

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<sup>10</sup> Fewer and fewer offices are taking applications in person. For the most part, you will apply either by telephone (by appointment only) or online.

<sup>11</sup> In one case a woman with pretty bad Crohn’s disease was found disabled in 2001. However, when her claim was reviewed, she had not been obtaining regular medical care and seeing her doctor frequently, all of which contributed to the decision to terminate her claim. *Guillot v. Astrue*, 2011 WL 4018681(E.D.La. June 22, 2011).

<sup>12</sup> Some states do not require that you request reconsideration. Follow the instructions in your denial letter or, once you are denied, get a lawyer who can walk you through the process.

often, by remanding the case (sending it back) to the Administrative Law Judge for reconsideration.

It is entirely possible that the SSA will propose or implement changes after the publication date of this *Handbook*. Thus, you should either get a lawyer or other representative, check the SSA website ([www.ssa.gov](http://www.ssa.gov)) to see how the procedures have been changed.

Over half of the claimants who appeal are granted benefits, which means that you should appeal if you are unsuccessful initially, at least up to the ALJ step. I know many patients who have been denied initially and on reconsideration, only to win at hearing.

### **E. The Disability Determination**

SSA defines disability as “inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months.” You must prove that you meet this definition to get SSDI.

The SSA has developed a **five-part test** for evaluating disability claims: First, is the claimant currently employed? If so, you lose. Second, does the claimant have a severe impairment? A severe impairment is one that “significantly limits his or her physical or mental capacity to perform basic work-related functions.” Third, does the claimant have an impairment medically equivalent to one specifically listed in the regulations, which list impairments as to which there is automatic eligibility (See Appendix F)? Fourth, if not, does the claimant’s impairment prevent him from performing work of the sort he has done in the past? Fifth, if so, does the claimant’s impairment prevent him from performing other work of the sort found in the economy (i.e., does the claimant have a “residual functional capacity”)? As to the first 3 parts of the test, medical evidence is necessary. As to the last 2 prongs, vocational evidence, often of a vocational expert, is required.<sup>13</sup>

The first of these tests is clear. If you are employed, you cannot get disability. Although one can earn up to roughly \$1000.00 per month<sup>14</sup> and still get SSDI benefits, if you are working at the time of your application, even if you earn that small an amount, you are taking a huge risk in that it will appear that you are able to work – simple as that.

Steps two and three, the finding that you have a severe impairment or an impairment that meets the listing, is paramount. Appendix F contains a table of contents for the listing of impairments, called the “Blue Book.” If you meet one of the listings, you are entitled to benefits with no further analysis; if you cannot show that you have a severe impairment (step 2), you are denied benefits. Please note that, under each listing, there are a number of *alternative* grounds

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<sup>13</sup> A vocational expert is someone who can testify about the jobs that exist in the economy and what functions are necessary to perform such jobs.

<sup>14</sup> The dollar limits on earnings are adjusted every year, so please check with the SSA to determine the limit in effect at any given time.

for finding disability. For example, under the listing for my illness, inflammatory bowel disease, you have to be found to have *either* an obstruction requiring hospitalization at least twice at least 60 days apart within a 6 month period OR two other manifestations (anemia, low albumin, abdominal mass, perineal disease, weight loss, or enteral or parenteral feeding) occurring within a 6 month period, *but you do not have to have all of these*.

Your task is to show either that you meet these criteria set forth in the listing, or that you suffer from a “medically equivalent” impairment. The things to emphasize in both steps two and three are the things that relate to the criteria in a listing. You may have additional symptoms that should be discussed, but try to fit your symptoms into the SSA criteria to show that you should be found disabled. If you don’t fit the listing perfectly, focus on showing that your disability is medically equivalent to the listed impairment.

If you have more than one medical condition, the combination of which results in a disability, the SSA will consider the whole picture. The combined effects of a primary chronic illness and other conditions should be considered in their totality. Do not make the common mistake of failing to detail the emotional toll the illness has on you and your family, as well as the basic functions you are unable to perform due to your illness. Look at the mental health criteria to see if you have a mental health disability in addition to your physical illness.

The primary evidence you present to establish that you have a severe impairment will be medical evidence. The SSA requires medical evidence to come from “acceptable medical sources,” which include licensed physicians, psychologists, optometrists, podiatrists, and speech-language pathologists. In addition, SSA requests information from hospitals, clinics or other health care facilities. Evidence from treating sources is given special weight.

SSA may ask for a report from the treating physician.<sup>15</sup> If so, such a report should include the following: medical history; clinical findings (results of physical exams, for example); laboratory findings; diagnosis; treatment prescribed with response and prognosis; and a statement of opinion about what the applicant can and cannot do. Clearly, this last item is critical. The statement should describe the ability to perform work-related activities such as sitting, standing, lifting, carrying, hearing, speaking and traveling. If there are mental impairments, the statement should include the patient’s ability to understand and remember, to respond to work demands, and to be appropriate in a workplace. For a child, the statement should describe limitations in learning, socializing, ability to care for him or herself, communication skills and ability to complete tasks.

There may be other evidence that you can present that would be helpful to show the extent to which a person’s impairments affect the ability to function. This may come from teachers, employers, co-workers, social welfare agencies, and other practitioners such as social workers, naturopaths, and so on.

The SSA may ask for a consultative examination. This may be performed by the treating physician if possible. However, an outside consultant will be utilized if the treating physician

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<sup>15</sup> You should give your treating physician a copy of this page so that he or she will know what items to address.

does not wish to perform the examination, does not have the right equipment to give SSA what it wants, there are inconsistencies in the file that cannot be resolved by further contact with the treating physician, or the claimant has a good reason not to want to return to the treating physician for this purpose. The report of the consultative examination should include the following: the claimant's main complaints; a detailed description of the history of the complaint; a description of both positive and negative detailed findings based on history, examination, laboratory and other tests, and any other abnormalities; results of any tests performed; the diagnosis and prognosis; a statement of what the patient can do despite his or her impairment, including the claimant's ability to do work-related activities such as walking, standing, sitting, lifting, carrying, hearing, speaking, and traveling, as well as functional abilities related to mental health impairments; and finally, a statement of the consultative physician's opinion and comments on the claimant's major complaints and other abnormalities, and his or her conclusions based on all of the available information.

If you have a particularly complex or difficult condition to diagnose and treat, you may want to check the Social Security website to see if the Social Security Administration has issued a ruling directing the way in which that particular condition should be analyzed. For example, there are rulings on chronic fatigue syndrome and fibromyalgia,<sup>16</sup> diagnoses that are determined based largely on subjective complaints of pain and fatigue for which there are no laboratory or other tests to confirm the diagnosis. Social Security Rulings (or SSRs) do not have the force of law. However, courts defer to the SSA's interpretation of its regulations unless they are clearly erroneous or inconsistent with statute or regulation. So if there is an SSR on your illness, you should try to show how your condition meets the criteria set forth in the SSR.

Finally, in developing evidence of symptoms involving some subjectivity, such as pain and fatigue, SSA will consider available information relating to daily activities; location, duration, and extent of pain; aggravating factors that increase the problems and symptoms; medications and their side-effects; measures the claimant has used to try to obtain relief; and other factors.

Once all of this is assembled and considered, steps two and three are concluded. If SSA finds that the claimant has an impairment that meets a listing, benefits are granted. If SSA finds that the claimant does not have a severe impairment, i.e., one that "significantly limits his or her physical or mental capacity to perform basic work-related functions," or a combination of impairments that do so, benefits are denied. If SSA finds that the claimant has an impairment that is severe although it doesn't meet a listing, the analysis moves to step four, a vocational analysis.

The first question in performing the vocational analysis is whether you are able to perform your most recent job. If so, you are not eligible. If not, then the question is whether, even with a severe impairment, you have sufficient "residual functional capacity" to perform other work available in the economy.

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<sup>16</sup> Social Security Ruling 99-2p. See *Ostalaza v. Astrue*, 2009 WESTLAW 3170089 (C.D. Cal. Sept. 30, 2009). There also are SSRs on how claims should be reviewed – for example, who constitutes an "acceptable medical professional" (SSR 06-03p). If you have any particularly difficult or unusual issue, it's worth searching the Social Security website for an SSR on point.



“Residual functional capacity” can be determined either by vocational expert testimony or by reference to grids published by the SSA. The grid is used when an impairment is exertional only, i.e., it has to do with lifting, standing, sitting, walking, etc. The grid charts a claimant as disabled or not based on physical capacity, age, education and work experience. If the use of the grid is appropriate, and the grid shows no disability, that decision is unlikely to be overturned on appeal.

If the disability is non-exertional, i.e., it involves pain, fatigue, cognitive abilities, etc., and if a finding is made that the non-exertional disability restricts performance of a full range of work, the non-exertional impairment must be taken into account, and the testimony of a vocational expert is necessary. Reliance on the grids alone is not permitted. Many chronic illnesses have both exertional limitations (for example, some patients can’t lift heavy items) and non-exertional aspects (for example, pain). As long as there are any non-exertional limitations flowing from the disability, SSA must produce the testimony of a vocational expert. You or your lawyer may wish to call your own vocational expert, and you certainly will want to cross-examine the expert the SSA relies upon. One of the important reasons to have a lawyer or non-lawyer representative at the hearing is because cross-examination is not as simple as it may appear, and this step in the process may well be the determining factor in your case.

The biggest problem that people with a chronic disease face is that we must show that we are unable to perform sedentary or light work. You have to be specific enough about how the disease affects your daily life to refute such a belief. Can you clean your house, drive, cook, shop? How many hours a day do you spend in the bathroom? Be detailed about your medications and their side effects. It is crucial that you explain in detail how your illness affects your daily life.

Don’t mince words. I recently read a case in which a court said that the claimant had testified that she needed ready access to a bathroom, but she had not stated that she had “soiled herself.” If you are fecally incontinent, say so. If there are other aspects of your illness that restrict your ability to work outside the home, this is not the time to be embarrassed – say it. You have to be clear and unambiguous in your testimony.

## **F. Supplemental Security Income**

Yet another layer of complexity exists when you are disabled but you haven’t earned 40 credits (for age 31 and over, 40 quarters or 10 years of contributions into the Social Security system through payment of FICA tax, 20 credits of which must have been earned in the last 10 years). This may be so because you are too young to have worked that many years, or you have been out of the workforce because you did not work while your children were young, for example. This makes you ineligible for SSDI.

Instead, you would apply for Supplemental Security Income, or SSI.

The disability determination for SSI is the same as for SSDI. The Blue Book listing of impairments applies equally to SSI. For children under age 18, disability is defined as “a

medically determinable physical or mental impairment or combination of impairments that causes marked and severe functional limitations, and that can be expected to cause death or that has lasted or can be expected to last for a continuous period of not less than 12 months.”

There is no waiting period under SSI, unlike SSDI. The applicant will receive benefits starting with the first full month after the patient applied or became eligible for SSI. In addition, under SSI, an applicant may be found “presumptively disabled,” allowing the applicant to receive benefits for up to 6 months while his or her application is being processed.

One of the best attributes of SSI is that, in most states, it comes with Medicaid. For children in particular, Medicaid has a special set of rules under the heading of Early and Periodic Screening, Testing, and Diagnosis (“EPSDT”). 42 U.S.C. § 1396d(r). EPSDT has probably the broadest coverage of any federally funded health benefit, including immunizations, vision services, dental services and many other features that are not available to adults on Medicaid. EPSDT covered services must be provided regardless of whether the state plan does not include all medically necessary services.

### **G. Social Security and Work**

The Social Security Administration encourages beneficiaries to try to work. If you are on SSDI, you can earn up to the amount that SSA considers to be “substantial gainful employment” without losing benefits. For 2011, that amount is \$1000 per month.

However, if, in 2011<sup>17</sup>, you earned \$720 per month or more for nine months within a 60 month period, that is considered a trial work period. During the trial work period, you will continue to receive SSDI benefits as long as you report your work activity and continue to have a disabling impairment. If you reach the end of the trial work period by earning \$720 or more for 9 months within a 60 month period, you then have 36 months during which you can work and still receive benefits for any month your earnings are not “substantial,” i.e., \$1000 or more in any given month. If your benefits stop because your earnings are not substantial, you have five years during which you can ask for immediate reinstatement of your SSDI benefits. You do not have to reapply or wait for your benefits to start while your medical condition is being reviewed. In addition, you retain your free Medicare Part A for 93 months after the nine month trial work period, and after that, you can buy Medicare Part A, and you can continue to pay your Medicare Part B premium, as well.

During the nine month trial work period, there is no limit to your earnings, and you still can receive benefits. During the 36 month extended period of eligibility, you cannot make more than \$1000 per month or your benefits will stop.

The rules are different for SSI. SSI payments are made based on income, so if you earn more than the SSI income limits, your benefits will end. The SSI income limit is different in every state. However, there is expedited reinstatement within 5 years if you find that you are

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<sup>17</sup> The dollar figures are adjusted to reflect cost of living increases each year, so you should consult the Social Security Administration for the dollar figures applicable for the year about which you are concerned.

unable to continue to work. Your Medicaid will continue until your income reaches a certain level. That level also is determined by each state.

There are several available resources if you want to try to get back into the workplace. The Ticket to Work program provides you with a “ticket” that allows you to obtain vocational rehabilitation, employment, or other support services from an approved provider of your choice. Work Incentives Planning and Assistance (WIPA) is designed to help you locate a work incentives organization that will help you find a job and provide information on the adequacy of health benefits in a particular job, or provide information about the availability of protection and advocacy services. States have vocational rehabilitation agencies and protection and advocacy programs, both of which are designed to help you re-enter the job market.

The trial work period with a five year period in which you can ask for reinstatement is a relatively risk-free way to test the waters, try to work, and get benefits reinstated if your attempt to work is unsuccessful and you remain disabled.

## **H. Basic Information About Medicaid and Medicare**

A comprehensive review of the Medicaid and Medicare programs is beyond the scope of this *Handbook*. However, I will provide some basic explanations, and point you in the direction of additional information.

Many millions of disabled people are covered by Medicare and Medicaid. The best resource I know of for consumers who are looking for information on Medicare and Medicaid was created by the Kaiser Family Foundation, and is available at the following website address: [www.kff.org/medicare/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=50946](http://www.kff.org/medicare/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=50946).

Because Medicaid is administered and funded at least in part by the states, and many states are operating under state-specific waivers, it is far more difficult to generalize about Medicaid than about Medicare.<sup>18</sup> Some states have coverage groups that go beyond those required by federal law. For example, in Connecticut, we have a coverage group of chronically ill children without an income test, but this is not a coverage group that all states have. Accordingly, generalization is difficult.

The only Medicaid coverage group that is required to be covered is called “categorically needy” – families who receive public assistance; pregnant women whose income is below 133% of the federal poverty level; children ages 6 to 19 whose family income is no more than 100% of the federal poverty level; caretakers who take care of children under age 19; SSI recipients; and institutionalized individuals whose income does not exceed 300% of the federal poverty level. The income limit for Medicaid will increase to 200% of the federal poverty level in 2014. The rest of the Medicaid coverage groups are optional.

The largest optional coverage group is the “medically needy,” who have more income and resources than permitted for the categorically needy. If a state has a medically needy option,

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<sup>18</sup> See brief discussion of Medicaid’s EPSDT program in Section VII.F, on SSI.

it must include pregnant women, children, newborns, blind, college students, caretakers, aged, disabled people on SSI.

Additional information about Medicaid can be found at [www.cms.hhs.gov/medicaid](http://www.cms.hhs.gov/medicaid). In addition, your state Department of Social Services or Human Resources – the agency in your state that administers the Medicaid program – will be able to answer your questions about your state's Medicaid plan. In addition, the Kaiser Family Foundation has a tremendous amount of information about each state's Medicaid program. You can find this information at [www.kff.org](http://www.kff.org).

As for Medicare, once you have been receiving SSDI benefits for two years, you are automatically eligible for Medicare. There are three parts to the Medicare program. The first two have been in existence for quite some time, so CMS and patients have had time to build a body of experience. These two parts are Part A, also known as Hospital Insurance, and Part B, also known as Medical Insurance. You do not have to pay for Part A, but there is a premium payment for Part B. Typically, your Medicare premium is deducted from your SSDI benefit.

In addition, we now have Medicare Part D, a prescription drug benefit. The best source of information about this new benefit that I know of is at the following web address: [www.familiesusa.org/site/PageServer?pagename=Medicare\\_Central\\_Index](http://www.familiesusa.org/site/PageServer?pagename=Medicare_Central_Index).

The new Medicare drug benefit covers all Medicare enrollees, including low-income enrollees who previously qualified for a drug benefit under Medicaid. That Medicaid drug benefit no longer will be available, and the Medicare drug discount card no longer will be operational, either. Anyone over age 65 who has Medicare Part A and/or Part B will be eligible to enroll in a prescription drug plan; only Medicaid recipients are enrolled automatically.

The Medicare drug benefit began in 2006 accompanied by much confusion. There are a number of different prescription drug benefit plans, at least some of which should offer broader coverage for a higher premium. However, if one is compelled to generalize, the Medicare drug benefit will work like this. Basically, you will pay a premium and an annual deductible, after which Medicare will pay a percentage of your drug costs until your total drug expenses reach \$2,840.00 (for 2011). At that point, Medicare ends and you are responsible for the full cost of your medications until your drug expense reaches \$4,550.00 (for 2011). This is called the "coverage gap" or "doughnut hole." Once your total drug expense reaches \$4,550.00, (for 2011) you will pay the greater of either a flat co-pay of \$2.50 for generics and \$6.30 for brand names or coinsurance of 5%.

The problems with the drug benefit are alarming for patients with chronic disease. By the time you reach \$4,550.00 and have a decent drug benefit, you will have paid a premium, a deductible, 25% up to \$2,840.00, and the doughnut hole of \$1,710.00. Even after that, 5% of expensive drugs can be an awful lot of coinsurance. For the patients I work with, this is likely to cause tremendous hardship.

Furthermore, each Medicare drug plan has a formulary, a list of drugs they will cover. If your medications are not on that plan's formulary, you will pay the cost of that drug. There is a



plan finder on the Medicare website that allows you to input a list of the medications you take to locate plans that cover those medications.

Be aware that, if you were getting your medications through a prescription drug patient assistance program described in Section V.C, above, if you are eligible for Part D, you no longer will be eligible for the patient assistance program.

In an effort to soften the effects of this change, the SSA and Centers for Medicare & Medicaid Services are offering “extra help” to low income seniors (for 2011, people with monthly income under \$1361 for a single person or \$1839 for a married couple and assets under limits set by Medicare). According to government publications being distributed by pharmacies all over the country, you may get some assistance even if your income is over these limits if you support other family members who live with you, or meet other criteria that SSA will require. For an Application for Help with Medicare Prescription Drug Costs, call 1-800-772-1213, or apply online at [www.socialsecurity.gov](http://www.socialsecurity.gov). Again, patients on Medicaid in addition to Medicare will be enrolled in this extra help program automatically. Some people will receive an application in the mail automatically. If they send you an application, it’s because they think you might be eligible, so you should fill it out.

You should be enrolled automatically in Medicare Part A (hospital) once you have received SSDI benefits for 2 years. The 2-year period starts on the date upon which you were entitled to disability (6 months after you begin to receive benefits), not the date when SSDI actually is paid. For example, if you apply for SSDI and it takes a year to get through the appeal process and be found eligible from the date of your application forward, the 2 years begins on the date of the application – the date you are found to have become eligible – and not the date when you receive your first check.

When you become eligible for Medicare, many Medicare Advantage Plans (private HMOs that administer the Medicare program) will be knocking at your door trying to get you to enroll in them. There have been reports of rampant misinformation as these Medicare Advantage Plans compete for your business. You may be told that you have to enroll in one of these plans; this is false. You may be told that you will not have access to your doctors if you don’t enroll in one of these plans; this is false. If I could give you one piece of advice about Medicare, it is do not enroll in a Medicare Advantage Plan. They have their own coverage criteria and do not necessarily cover everything that traditional Medicare covers. I have not had to file a single appeal in traditional Medicare, but from the time the Medicare Advantage Plans started signing up enrollees, I have had to file several appeals – appeals that would not have been necessary under traditional Medicare. Why go to an HMO when you can have free choice under traditional Medicare? The Medicare Advantage Plans not only cost the federal government more, but they are more restrictive in providing services.

Last, a word about coordination of benefits – what to do if you have private health insurance through a job or a spouse’s job when you become eligible for Medicare. Medicare Part A is automatic, but you have to sign up for Parts B and D. If Medicare is primary, which it is in most cases, then your private insurance may well require you to sign up for Medicare Part B, or the plan may treat you as if you did, in which case the private insurance would pay only

what a secondary plan would pay. In addition, if you do not sign up for Medicare when you first become eligible, you may face a penalty when you do join. So if you have private insurance, do not assume that you can turn down Medicare and stick with what you have. Unless Medicare would be secondary – generally, unless you or your spouse is an active employee of an employer with a large group plan (over 100 members) – you are required to sign up for Medicare when you are eligible to do so.

Finally, the difficulty of piecing together Medicare coverage information from all of the available sources cannot be overstated. There are several different Medicare Manuals, for example. There is a Coverage Manual, which you would expect to contain most of the available information about coverage issues. However, that Manual is not as comprehensive as its title implies. There are separate Manuals for Hospital, Home Health Care, Skilled Nursing Facilities, Rehabilitation Facilities, etc. This makes painting a unified picture challenging, at best. There is a tremendous amount of information at [www.medicare.gov](http://www.medicare.gov). There is more detailed coverage information on coverage issues at [www.cms.hhs.gov/mcd/index\\_list.asp?list\\_type=nc](http://www.cms.hhs.gov/mcd/index_list.asp?list_type=nc). This website lists National Coverage Analyses (“NCA”) and National Coverage Determinations (“NCD”).

In addition, there is a State Health Insurance Assistance Program or SHIP in every state. Their job is to help you understand your various Medicare plan options. To find your state’s SHIP, go here: <https://www.shiptalk.org/About/SHIPProfileSearchForm.aspx?mf=Display>.

## **I. Social Security Disability and the Courts**

Even though Social Security Disability is a federal program based on federal statutes, regulations and policies, there are slight differences of interpretation among the courts of which you, and particularly your attorney, should be aware. The federal courts are organized into Circuits; you should look primarily at the Circuit in which your State is located. For example, the cases relating to the weight to be given to the treating physician’s opinion vary in important ways. Appendix I contains some opinions in the various jurisdictions on issues where the courts are not in full agreement. The SSA in your jurisdiction is bound by the cases in your Circuit. In addition, in the absence of private insurance cases on your disease, you may use SSDI cases as persuasive authority in private disability insurance appeals.

The federal courts’ rulings on SSDI and SSI are binding on the SSA. The cases will give you guidance on how the SSA criteria will be interpreted, and therefore will help you to make your case to the SSA. Again, emphasize the things the SSA and the courts say are important.

The federal Courts of Appeals (or Circuits) bind the lower federal District Courts. So the best case law you can cite in your jurisdiction will be the Circuit court, with District Court decisions also being helpful, but not quite as strong authority. Newer cases are better authority than older ones, but the most important thing is the similarity in the facts between your case and the case before the court. If there are no similar cases in your jurisdiction, you can refer to cases in other jurisdictions, but with the understanding that they are persuasive only, and not binding on the courts in your jurisdiction.

See Appendix I for a discussion of differences among the jurisdictions.

### **J. State Disability Benefits**

There are some states that provide disability benefits. The good news is that coverage usually kicks in faster than Social Security benefits. The bad news is that, in most states, it is a temporary benefit and doesn't pay an awful lot. Still, it is better than nothing and might get you through the period while you are waiting for Social Security.

As best I can tell, the states that currently have disability benefits are New York, New Jersey, California, Rhode Island, and Hawaii. Other states may have programs that I cannot readily find on the internet, and several states provide disability insurance for state employees.

If you believe you are disabled, search your state's official website and see if there are disability benefits available to you.

## **VIII. Discrimination in Employment, Public Accommodations, and Medical Leave**

Another area of law that patients with chronic disease need to understand relates to discrimination – whether to disclose the disease in a job application or interview; what accommodations an employer is required to make; what amounts to employment discrimination; if there has been discrimination, what to do about it; whether medical leave must be permitted and for how long; and whether there must be access to a bathroom or other assistance in a public place or job site.

There are both state and federal laws relating to these issues. This *Handbook* focuses on federal law; you should consult your state's civil rights agency to see if your state's law is more liberal than the federal law in any way.

There are a number of different statutes, or parts of statutes, that could affect patients that I will not address here, including, for example, the provisions applying to state and local government, or the Architectural Barriers Act. Summaries of these statutes are found on the Department of Justice's website, [www.usdoj.gov](http://www.usdoj.gov). For present purposes, I will focus on the employment aspect of the Americans with Disabilities Act.

### **A. Americans with Disabilities Act**

The Americans with Disabilities Act ("ADA")<sup>19</sup> prohibits discrimination on the basis of disability in employment, state and local government, public accommodation, commercial facilities, transportation and telecommunications. The ADA grew out of the Rehabilitation Act of 1973, which prohibits discrimination on the basis of disability in programs conducted by the federal government, in federal financial assistance, federal employment, and the employment practices of federal contractors. This may sound narrow, but section 504 of the Rehabilitation

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<sup>19</sup> 42 U.S.C. § 12101 *et seq.*

Act reaches any employer who receives federal funding, which includes a very broad spectrum of employers.<sup>20</sup> The standards for determining whether discrimination has occurred are essentially the same under the two Acts.

In general, to be protected by the ADA, (1) one must be a person with a disability, defined as a person who has a physical or mental impairment that substantially limits one or more major life activities; or (2) have a history of such limitation; or (3) be perceived to have such limitation.

For purposes of this *Handbook*, I will focus on the two portions of the ADA that have the greatest effect on patients with chronic illnesses: employment and public accommodations. The federal government has provided excellent web and telephone-based services pertaining to the ADA. The website and other links are at [www.usdoj.gov/crt/ada](http://www.usdoj.gov/crt/ada). The ADA technical assistance line is 1-800-514-0301. Another place to look for employment-related materials is the website of the Equal Employment Opportunity Commission (“EEOC”), [www.eeoc.gov](http://www.eeoc.gov). These are excellent places to start. Indeed, much of what follows is a summary of the information provided on this website, as well as the ADA technical assistance manual, which is available online as well.

Throughout this section, please pay particular attention to underlined words or phrases. It is the definitions of these words and phrases that will determine whether you may be entitled to relief under the ADA.

#### i. Employment

Title I of the ADA relates to employment. It applies only to employers with 15 or more employees in 20 nonconsecutive workweeks of the current or preceding calendar year, and requires such employers to provide an equal opportunity to benefit from the full range of employment-related opportunities to individuals who are (a) qualified, in part because they can perform the (b) essential functions of the job, who (c) have a disability. It prohibits discrimination in recruitment, hiring, promotions, training, pay, social activities, and other privileges of employment. For example, it restricts questions that can be asked about an applicant’s disability before a job offer is made (*see* Appendix J for rules pertaining to job interviews), and it requires that employers make (d) reasonable accommodations to the known physical or mental limitations of otherwise qualified individuals with disabilities unless it results in (e) undue hardship.

The ADA applies only to employees. It does not apply to independent contractors. Some employers use the independent contractor label to avoid payment of benefits, as well as to avoid application of anti-discrimination laws. The determination of whether a particular individual is an employee or independent contractor is based on a long list of factors. Even if the employer calls someone an independent contractor, the label is not determinative if the individual is treated as an employee in other ways. This includes, but is not limited to, whether the individual receives employee benefits such as health insurance and paid vacation leave, and whether he or

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<sup>20</sup> As will be discussed in detail below, both the ADA and Section 504 of the Rehabilitation Act also apply to school-based discrimination and accommodations.



she performs the exact same work and reports to the same supervisor as someone characterized as an employee. An exhaustive discussion of this issue is beyond the scope of this *Handbook*. However, if you are called an independent contractor by your employer, you should be aware that one very significant hurdle you will have to overcome in asserting rights under the ADA is establishing that, in fact, you are an employee.

The following five sections are intended to explain each of the five phrases underlined above, which, taken together, determine whether an ADA claim may succeed.

#### a. Qualified Individual

A qualified individual is defined as someone who meets legitimate skill, experience, education, or other requirements of an employment position that she or he holds or seeks, and who can perform the essential functions of the job, with or without reasonable accommodation. Individuals should not be considered unqualified because of their inability to perform incidental job functions; if the individual is qualified to perform essential job functions except for limitations caused by a disability, the employer must consider whether the individual could perform these functions with a reasonable accommodation.

The determination of whether a person is qualified is made in two steps. This decision should be made at the time of the employment decision, based on the capabilities of the person with the disability at the time of the employment decision rather than on speculation that the employee may become unable to perform the essential functions of the job in the future, or that he or she will cause increased health insurance premiums or worker's compensation costs.

The first step in determining whether a person is qualified is to determine whether the person satisfies the prerequisites of the position, such as possessing the right skills, experience, and education. For example, to determine whether an attorney with a chronic illness is qualified, the first step is to determine whether the attorney is licensed to practice law, with the experience needed for the particular position. This is a relatively straightforward determination, as it would be for any person applying for, or holding, a job.

#### b. Essential Functions of the Job

The second step in determining whether a person is qualified is the determination of whether the person can perform the essential functions of the job, with or without reasonable accommodation. The purpose of this step is to ensure that persons who can perform essential functions are not denied employment opportunities because they are unable to perform incidental or marginal functions of the job.

The term essential functions means the fundamental job duties of the employment position the individual with a disability holds or desires. A function may be essential because the position exists solely to perform that function, or because of the limited number of employees available among whom the performance of that job function can be distributed, or because the function is so highly specialized that the person is hired due to his or her expertise in performing precisely that function. Evidence of whether a particular function is essential includes the

employer's judgment, written job descriptions prepared before advertising or interviewing applicants for the job, the amount of time spent on the job performing the function, the consequence of not requiring the individual to perform the function, the terms of a collective bargaining agreement, the work experience of past persons in the same job, and the current experience of others in similar jobs. If the individual who holds the position actually is required to perform the function the employer claims is essential, the question then is whether removing the function would fundamentally alter that position.

Some examples may be helpful. If, for example, an employer states that typing is essential, but other or previous people in the same position were or are not required to type, this would be evidence that the function is not essential. If someone is hired to proofread documents, the ability to proofread documents would be essential, but photocopying those documents may not be. A function that might be essential in the context of a small staff in which it is difficult to reassign the function might not be essential in the context of a larger staff. In the alternative, if someone is hired based on his or her expertise and skill to perform a specialized function – say a computer programmer is hired to perform a very specialized task – that particular function is essential. Alternatively, if someone spends the majority of his time answering telephones, this would be evidence that answering telephones is an essential function.

As these examples show, the determination of whether a function is essential must be made on an individualized basis. For the protection of both employer and employee, having a written job description is the best way for the parties to be clear on which functions are essential.

Of particular concern to patients with chronic diseases, attendance is an essential function of a job in which employees typically are required to be present in the workplace. Although some employers may be able to provide reasonable accommodations, as discussed below, if your job requires your presence and you are unable to be present, you are unable to perform the essential functions of your job and, thus, you are not a qualified individual with a disability, and will not be protected under the ADA.

Finally, an employer need not adjust its performance standards with respect to the essential functions of the job. If social workers are required to handle 20 cases, then the employer will not be liable for refusing to lower that standard, as long as the employer enforces this same standard with respect to all other employees. If an employer raises production standards in an effort to preclude an individual with a disability from being capable of performing the job, then the employer may have to show that there is a legitimate, nondiscriminatory reason for this increased standard.

### c. Disability

Assuming an individual is qualified, both based on education, skill and experience, as well as an ability to perform the essential functions of the job, the next step is to determine whether he or she has a disability. To be found to have a disability, one must have: (i) a physical or mental impairment that (ii) substantially limits (iii) one or more major life activities, have a record of such an impairment, or be regarded as having such an impairment.