failing to disclose the potential effects of drugs,[63] and other product liability cases.[64] And, of course, there are medical malpractice cases.[65] In addition, as one would expect, there are a number of lawsuits over coverage under an insurance policy.[66] Most relate to pre-existing condition limitations.[67] However, there are cases that hold that insurers were correct in denying bone marrow transplantation for Crohn's disease because it is experimental/investigational.[68] As explained above, cases involving insurance claims that are employment-based are subject to ERISA's very high burden of proof. (*See* Section V.B.ii, above). However, there are cases in which courts have found that a plan administrator's decision to deny benefits was found to be "arbitrary and capricious."[69]

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student loans in *In re Jara*, 2006 WESTLAW 2806556 (Bktrcy. D. N.J. Sept. 27, 2006).

[63] *See, e.g., Mauldin v. Upjohn Co.*, 697 F.2d 644 (5th Cir. 1983).

[64] *See, e.g., Mattis v. Carlon Electrical Products*, 295 F.3d 856 (8th Cir. 2002) (apprentice electrician sued manufacturer of PVC cement to recover for reactive airways dysfunction syndrome (RADS) he claimed to have acquired due to exposure of the cement); *Meister v. Medical Engineering Corp.*, 267 F.3d 1123 (D.C. Cir. 2001) (patient with scleroderma unsuccessfully sued manufacturer of silicone breast implant claiming that the implant caused the scleroderma; court held there was insufficient evidence to show a causal connection between the implant and the disease).

[65] *See, e.g., Haley v. United States*, 739 F.2d 1502 (10th Cir. 1984), in which the court affirmed a jury verdict based on the facts that physicians performed surgery on an IBD patient without reviewing her past medical records, without arriving at a definite diagnosis before surgery, and without informed consent.

[66] As explained in section IV.B., many health insurance claims can be brought – indeed, the majority of claims based on employment-based group health insurance in general must be brought – in federal court under ERISA, where a very high burden of proof makes it difficult for patients to prevail. *See, e.g., Scott v. Hartford Life and Accident Ins. Co.*, 2004 WESTLAW 1090994 (E.D.Pa. 2004) (applying arbitrary and capricious standard in long-term disability case when the policy gives the plan administrator discretionary authority to determine eligibility for benefits); *Gerhold v. Avondale Industries, Inc.*, 2004 WESTLAW 602778 (E.D.La. 2004) (same). There are, of course, other types of cases involving insurance. For example, in *Metropolitan Life Ins. Co. v. Robinson*, 2007 WESTLAW 2461658 (N.D.Ill. Aug. 27, 2007), the court found that an insurer could not rescind a disability insurance policy due to false answers in the application for the policy when it was unclear whether the insured intentionally deceived the insurer.

[67] For example, in *Franceschi v. American Motorist Ins. Co.*, 852 F.2d 1217 (9th Cir. 1988), the court found that a pre-existing condition limitation, precluding payment for "medical treatment" for the first 12 months of coverage, did not apply to a colonoscopy because it was not "medical treatment." In *Marek v. Amba Marketing Systems, Inc.*, 1989 WESTLAW 4141 (9th Cir. 1989), the same court found that a condition is pre-existing when the symptoms manifest themselves, even if the condition has not yet been diagnosed. *See also Duckett v. Blue Cross and Blue Shield of Alabama*, 123 F.Supp.2d 1286 (M.D.Ala. 2000) (finding that Crohn's disease was a pre-existing condition based on independent medical examiners (IMEs)).

[68] *Parsons v. Sisters of Charity of Leavenworth Health System, Inc.*, 2011 WL 2144894 (D. Mt. May 31, 2011).

[69] *See, e.g., Whealen v. Hartford Life and Acc. Ins. Co.*, 2007 WESTLAW 1891175 (C.D.Cal. June 28, 2007) (denial of long-term disability benefits overturned when insurer took inconsistent positions, failed to adequately investigate claims of cognitive impairment secondary to chronic fatigue syndrome, and failed to credit the credible report of the treating physician); *Donovan v. Eaton Crop. Long Term Disability Plan*, 462 F.3d 321 (4th Cri. 2006) (long-term disability denial was reversed when not supported by substantial evidence); *Collins v. Continental Casualty Co.*, 2004 WESTLAW 120235 (8th Cir. 2004) (denial of long-term disability benefits due to chronic pain was not supported by sufficient evidence when plan administrator inappropriately discounted subjective reports of pain that were not tied to a definitive diagnosis); *Audino v. Raytheon Co. Short-term Disability Plan*, 2005 WESTLAW

In one particularly unusual federal case, an airline passenger with chronic respiratory problems died when her carry-on bag, which held her medication and a breathing device, were seized and not returned to her in a timely manner.[70] Her survivors filed suit under the Warsaw Convention. The passenger's daughter testified that she told the ticket agent that her mother's suitcase contained her medication and breathing device, so that the airline would make sure that her suitcase would stay with her as she proceeded to connecting flights, until she reached her destination in Guyana. In fact, the daughter heard the ticketing agent speaking with a contact person in New York, where her mother would be changing planes. However, while making her connection in New York, the patient was required to relinquish her suitcase. She was promised that she would have the bag back as soon as she reached her destination. That did not happen. Day after day, she was told that the bag would be on the next flight, and each day, that did not occur. After two days, she was hospitalized and later died. The court found that the seizure and misplacement of the suitcase was an "accident" for purposes of the Geneva Convention, and that this "accident" caused the passenger's death.

Similarly, in the state courts, there are a whole host of cases somehow involving chronic illness. There are divorce cases in which a disease is relied upon as a basis for claiming alimony from a healthy spouse, or health insurance coverage, or assistance with medical bills.[71] There are workers' compensation cases;[72] state law employment discrimination claims;[73] a case in

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846234 (5th Cir. 2005) (denial of short-term disability benefits to patient with rheumatoid arthritis and optic neuritis was an abuse of discretion when plan administrator characterized test results as normal when they were barely normal, and ignored documented symptoms, such as swollen joints); *Stup v. UNUM Life Ins. Co. of America*, 390 F.3d 301 (4th Cir. 2004) (denial of long-term disability benefits to patient with lupus and fibromyalgia was an abuse of discretion when treating physician opined that she could not perform even sedentary work for more than two hours at a time, instead relying on a functional capacity examination (FCE) that was inconclusive). Even when the deferential "arbitrary and capricious" standard applies, there are times when a court will reverse an insurer when the insurer's decision is not supported by substantial evidence on the record as a whole. *Johnson v. Continental Casualty Co.*, 2006 WESTLAW 852388 (E.D.Mo. March 31, 2006) (insurer failed to demonstrate a meaningful consideration of cognitive limitations associated with cluster of autoimmune diseases).

[70] *Prescod v. AMR, Inc.*, 383 F.3d 861 (9th Cir. 2004).

[71] *See, e.g., Parker v. Parker*, 639 So.2d 1376 (Alabama App. 1994); *Paul v. Paul*, 1993 WESTLAW 445902 (Connecticut Superior Court 1993). *See also Smith v. Smith*, 969 S.W.2d 856 (Missouri Court of Appeals 1998) (when father suffered from Crohn's disease and was on leave from work without pay, it was error for the court to award child support as if the father was working full-time); *In re the Marriage of Williams*, 2005 WESTLAW 92247 (Washington Appeals 2005) (wife with undifferentiated autoimmune disease characterized by inflammatory arthritis and Raynaud's phenomenon was given alimony that would decrease as she was able to re-enter the workforce).

[72] *See, e.g., Delaney v. Alaska Airlines*, 693 P.2d 859 (Alaska 1985) (worker must establish a link between the employment and the disability, and Crohn's patient failed to establish that on the job stress caused his disease); *Christensen v. Saif Corp.*, 698 P.2d 966 (Oregon Court of Appeals 1985) (claimant failed to prove that work-related stress was the medical cause of his ulcerative colitis); *Martin v. Bonnevilla Homes*, 2003 WESTLAW 21496607 (Nebraska Appeals 2003) (patient with myasthenia gravis sued that work-related accident "set off" his disease); *Hensarling v. Casablanca Construction Co., Inc.*, 2005 WESTLAW 757305 (Mississippi Appeals 2005) (patient claimed that exposure to toxic chemicals in the workplace caused anemia, neutropenia, and leucopenia).

[73] *See, e.g., Hobson v. Raychem Corp.*, 73 Cal App.4th 614 (California Court of Appeal 1999) (employee claimed a violation of the state anti-discrimination law, but the court found that her ulcerative colitis was not a "substantial impairment."); *Griffith v. Boise Cascade, Inc.*, 45 P.3d 589 (Washington 2002) (patient with polymyositis, an

which a lawyer was disbarred for breaching obligations to clients, even considering ulcerative colitis as a mitigating factor;[74] claims against drug manufacturers for failure to warn of the effect of a medication on pre-existing condition;[75] and a whole host of other claims. The cases are more varied than I ever could have imagined. In fact, I even found a case in which the plaintiff claimed that she ate a Hershey's "Mr. Goodbar" candy bar without noticing that it was full of worms, developing ulcerative colitis as a direct result!!![76]

In addition, as I explained in Section V.B.ii, state regulation of insurance is exempt from the reach of the federal ERISA law, which otherwise governs employer-based group insurance plans.[77] Thus, there are state court cases relating to private insurance.[78] Further, state courts would be the most likely forum for medical malpractice cases involving a chronic disease.[79] For example, a patient sued for malpractice when she contracted hepatitis-C from a blood

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autoimmune disease that results in muscle pain and weakness, sued for failure to accommodate her disability and, ultimately, job termination); *Doyle v. Maine Dept. of Human Services*, 2002 WESTLAW 1978907 (Superior Court of Maine 2002) (applying ADA criteria to determine that employee with ulcerative colitis was not a qualified individual with a disability); *Potvin v. Champlain Cable Corp.*, 687 A.2d 95 (Supreme Court of Vermont, 1996) (under state Fair Employment Practices Act, employee with ulcerative colitis was unable to work evening shift, and even though the disability lasted 5 months, that was sufficiently long so that it was not too fleeting to be covered by the Act).

[74] *Ainsworth.v. State Bar of California*, 46 Cal.3d, 1218, 762 P.3d 431 (California 1988).

[75] *Bluestein v. Upjohn Co.*, 430 N.E.2d 580 (Appellate Court of Illinois 1981) (the patient lost).

[76] *Kassouf v. Lee Bros., Inc.*, 26 Cal. App.2d 568 (California District Court of Appeal 1983).

[77] Other state law issues may be exempt from the reach of ERISA, as well. For example, in *Westinghouse Electric Supply Corp. v. Massachusetts Comm'n Against Discrimination*, 1999 WESTLAW 140492 (Massachusetts Superior Court 1999), the court found that ERISA did not pre-empt a case brought under state employment discrimination laws even though one consequence of the wrongful termination was the loss of benefits that were governed by ERISA.

[78] *See, e.g., Aetna Life Ins. Co. v. Lavoie*, 470 So.2d 1060 (Alabama 1985) (Alabama Supreme Court upheld a jury finding that the health insurer denied a claim submitted on behalf of a patient with ulcerative colitis and unrelated psychiatric problems in bad faith, along with an award of punitive damages in excess of $3 million when the insurer failed to obtain and/or review hospital records for the inpatient stay that was the subject of the claim that was denied.); *Life General Security Ins. Co. v. Cook*, 648 So.2d 237 (Florida Court of Appeals 1994), (insured challenged a pre-existing condition limitation when the actual diagnosis had not been made when the coverage commenced, but the symptoms were present and were being treated.).

[79] *See, e.g., Oxment v. Wilkerson*, 646 So.2d 4 (Alaska 1994) (negligence in inserting a "catheter" in the chest (what I would have called a port), causing a cardiac problem and subsequent surgery); *Kranda v. Houser-Norberg Medical Corp.*, 419 N.E.2d 1024 (Court of Appeals of Indiana 1981) (plaintiff with Crohn's disease had surgery to remove vaginal warts and a cyst, and claimed that the surgeon failed to explain to her the risk that this surgery could lead to fistulas and other Crohn's-related issues; verdict for physician upheld); *Gamino v. Lakeside Hospital*, 652 So.2d 36 (Louisiana Court of Appeals 1995) (the court held that physicians did not commit malpractice when constructing a flat stoma rather than a Brook's stoma, even though physicians testified that a Brook's stoma is preferable); *Lavoie v. Jackson*, 2001 WESTLAW 1006670 (Rhode Island 2001) (patient sued for failure to timely diagnose thyroid cancer, especially since she had Hashimoto's thyroiditis, which physician had been treating for years).

transfusion.[80] Another patient's family sued for malpractice and wrongful death for failure to diagnose a rare skin condition called pemphigus vulgaris.[81]

This list of types of legal issues facing patients with chronic illnesses could go on and on. It seems as though patients not only have to understand their medical conditions, but many also have encounters with the legal system in a wide variety of contexts, both expected and somewhat surprising. It would be impossible to anticipate all the issues that might face every patient here. If you encounter issues other than those addressed here, my first preference always is to attempt a negotiated resolution, but if all else fails, retain counsel.

There are a number of ways to find counsel appropriate for a particular circumstance. I already have mentioned NOSSCR, the organization of attorneys who take SSDI cases. The National Employment Lawyers Association (NELA) is a good place to start to find a lawyer in the employment context (either ADA or FMLA). A nationwide directory of lawyers known as Martindale Hubbell has a website where you can type in a specialty and a geographic area, and obtain a list of attorneys who work on the issue as to which you need assistance. *See* www.martindale.com/xp/Martindale/ home.xml. Similarly, bar associations may track the specialty of its members, who often join "sections" that focus on particular areas of the law. The trick to using a large directory or bar association is to figure out which lawyers represent plaintiffs (you) as opposed to defendants (insurers, employers, etc.). You often can tell if their firm lists a number of their clients, which many law firms do. The presence of lots of corporate clients probably means the firm generally does defense work. In the alternative, if you have an attorney who has helped you in another context, often he or she can provide a referral.

If this *Handbook* doesn't give you everything you need to know, there are attorneys around the country who can and will help. You may have to be enough of an advocate for yourself to find someone to take your case, but if your case has merit, you should be able to find help in the legal community.

XIV. Advocacy Outside of the Legal Context

There are other ways in which we must be our own advocates that have no direct relation to the law. I will mention two experiences of mine as examples.

I went to a doctor in New York for a renal consult. I had been driven from Connecticut, and there were no parking garages right near the doctor's office, so I'd had to walk quite a long distance – it seemed like miles to me, as sick as I was. When I arrived, I was asked for my insurance card. I said sure, but I need to use the bathroom right away. The receptionist said she needed my insurance card first. I explained that I have Crohn's disease and again said I would give her everything she wanted if she would let me go to the bathroom first. She refused, and, of course, I did not quite make it to the bathroom. The doctor and office manager's apology were cold comfort.[82]

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[80] *Miller v. Southern Baptist Hospital*, 806 So.2d 10 (Louisiana Appeals 2002).

[81] *Rivera v. County of Suffolk*, 290 A.D.2d 430 (New York Supreme Court, Appellate Division 2002).

[82] Many IBD patients have had similar experiences. Some of the Chapters of the Crohn's & Colitis Foundation of

Even more recently, I went for a small bowel series at a New York radiology facility. About a month earlier, I'd had scans done at the same facility. My insurance had paid some of the charges, and I had sent the provider a large portion of the cost of the scans, but I was waiting for some additional information my insurer asked me to obtain before finally disposing of the claim. As I sat freezing cold in a hospital gown after drinking barium, I was asked to join a woman in a small room. She closed the door and asked why I had not yet paid for the earlier test. I said that I'd endorsed over an insurance check for nearly $1,200, that my insurer was still processing the rest, and that I had only gotten a bill about 10 days earlier. I was told that I was lucky that I'd already ingested the barium or they would not have performed the test without payment for the previous procedure, despite the fact that they'd sent me a bill fewer than 30 days before. It turned out that the insurance check along with my letter explaining the status of the claim was on the desk of someone who was on vacation that week.

Because we have so much contact with the medical profession, we all have stories like these. Although neither presents a legal issue, if we say nothing when we are treated this way, the attitudes that lead to this treatment will never change. In both of these cases, I wrote what I believe were professional but candid letters afterwards. In both cases, I got express written apologies, assurances that disciplinary action had been taken, and promises that this sort of conduct would not be repeated. Did I change the world? No. But maybe I got through to one person who thought they could treat me as less than human. Maybe the next patient won't be treated the same way.[83]

The point I want to leave you with is that everything we do to educate our doctors, fellow patients, insurance companies, the Social Security Administration, employers, courts, legislators and our families and friends pays off for others with chronic illness. Even without a law degree, there is much that patients can do to change things for the next patient who comes along.

America have been working tirelessly to get legislation passed that would require stores with employee bathrooms to let us use those bathrooms. This sort of advocacy – advocacy in the legislative arena, especially at the state level – is not as hard as it sounds. Call your state representatives when something like this happens, especially in a public place. If we don't complain about it, it surely won't get fixed.

[83] Of course, I do not attribute such behavior to all doctors' offices, and do not intend to imply any generalization of what I hope are exceptions to the rule.

XV. Conclusion

Although I am sure that I have not answered every question patients might have about health and disability insurance, SSDI, discrimination, family and medical leave, and educational equity, I hope I have given patients enough information to understand the system when they cannot obtain the assistance of an attorney. Remember – it is up to us to be our own advocates, even when we have attorneys. Indeed, you may have to advocate with your attorney! Use what is here as a guide to help you ensure that you get the best possible results for yourself. Good luck!

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