



The Carousel Network

**Chronic Neuroimmune Disease
Information and Support for Sonoma County**
122 Calistoga Road, #216
Santa Rosa, CA 95409
www.cndsinfo.net

HMO Patient Self-Defense Kit

*Excerpted from
Making A Killing: HMOS and The Threat To Your Health
Foundation for Taxpayer and Consumer Rights*

Kaiser Permanente and other HMOs are very good at making patients with complaints go away. It is even easier to get rid of patients with CFS/FM, MCS and other difficult-to-diagnose-and-treat disorders and diseases because the patients tend to be sicker and suffer from cognitive dysfunction.

“The greatest mistake patients in need of critical care and their loved ones make is the assumption that the system is there to help them.”

The above quote, like the rest of this guide, is excerpted from the FTCR’s book, Making A Killing: HMOs And The Threat To Your Health. This guide simplifies the process while teaching you how to be the squeaky wheel who gets the services in the managed care machinery.

The Carousel Network (TCN) offers information on the various diseases and disorders associated with chronic neuroimmune diseases, such as chronic fatigue syndrome, fibromyalgia, multiple chemical sensitivity, autoimmune thyroid disease, etc. The information is intended to help patients and caregivers make informed decisions about the patient’s health, diagnostic testing, and treatment in conjunction with their health care practitioners. TCN does not diagnose patients nor recommend specific medical or palliative treatments.

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Membership is \$20/year; make checks payable to The Carousel Network, POB 366, Fulton CA 95439-0366.***

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Excerpted from
Making A Killing: HMOS and The Threat To Your Health
The Foundation for Taxpayer & Consumer Rights
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Corporate medicine is, by self-admission, intent on shackling health care expenses by doctors and other medical professionals against the interests of patients. For the patient denied treatment, this is an adversarial system.

Unfortunately, a seriously ill patient in need of a medical treatment is disabled--by definition, least able or unable to advocate for themselves.

The greatest mistake patients in need of critical care and their loved ones make is the assumption that the system is there to help them. Doctors and nurses may be there, but they do not control the corporate medical system. Often, it is a friend or family member who must lead the battle for a patient's care and they must remember that a likely response from the system will be delay and denial. How can patients or their allies help themselves in a system that is set up not to help them get treatment? Your tactics must be those of negotiation.

Everything is negotiable--with the HMO, the HMO doctor, the HMO hospital. In a negotiation, establishing what is reasonable is the goal.

- What should a reasonable person have to do in order to document his or her need for treatment?
- What should a reasonable corporation have to provide and how long should it take?
- Is the company living up to the letter and spirit of state law?

These are the types of standards someone negotiating with their HMO or HMO doctor must fight for. The record has indicated that HMOs do not concede expensive treatment without constant and repeated demands.

HMOs have time on their side and they know it. They will delay as a tactic of denial. Enough delays will equal a denial for a patient in need of critical care. Because most patients cannot sue HMOs for a denial or delay of treatment and receive damages if they prevail, the company has an incentive to stonewall because there is no financial penalty. (See Chapter Five)

Reasonableness always includes a reasonable timetable. When will a decision be made to approve the care? Who is the decision-maker? How long will it take to schedule the procedure? What is the longest it will take before this doctor sees me?

The tactics of getting care from an HMO or HMO doctor may be no different than those involved in any other struggle against bureaucratic power. The major difference is that the patient is typically not in any condition to fight. That is why others close to them must take on that role. Patients themselves should make such contingency plans.

And even for the well, fighting for a just cause, such as with an HMO or HMO doctor for medically-appropriate treatment, is not an ordinary activity of daily living.

The fight begins with an understanding of the system and its foibles.

There are also some general rules one can always follow in dealing with HMOs, but these are no panacea, simply precautionary measures.

- Write everything down. Bring a notepad and pencil to all medical facilities and take notes on what your doctor tells you. This may feel uncomfortable, but it will help to keep track of your care, catch any errors, and provide a record should there be a question of inappropriate treatment.
- If you are denied care, ask for it in writing. You will need a record of the denial if you want to dispute it. Memorialize in written correspondence all conversations if it becomes apparent that you are not receiving cooperation. Leaving a "paper trail" often helps to get results.
- Find out the timelines. Most states have regulations establishing the timeframe within which a

treatment or coverage decision must be made. Contact the appropriate regulatory authority in your state and find out what those timelines are. Then make sure everyone you deal with at the medical group or the HMO know that you know what those timelines are and make sure they stick to them. Also, as part of their marketing, most HMOs are accredited by non-government groups such as National Committee for Quality Assurance [www.ncqa.org], American Accreditation HealthCare Commission/URAC [www.uran.org] and the Joint Commission on Accreditation of Health Care Organizations [www.jcaho.org]. These organizations often have timeline requirements even more stringent than the state requirements. Find out if your HMO is a member of any of these organizations and if it is, find out that organization's timeline requirements for the health plan's decision-making process. Again, make sure the HMO knows that you know those timelines and that you expect them to be followed.

- Appeal a treatment denial to regulators. HMOs are regulated by the state regulatory agencies, many of which have a consumer complaint hotline. The rules for each state differ. Find the appropriate state agency and their rules for filing a complaint. Medicare and Medicaid recipients can take a complaint to the federal Health Care Financing Administration. (WARNING: Don't rely on governmental agencies as your savior, however, because many are ineffective. Patients must be persistent if they hope to get a response from an HMO or government.) HMOs do not like too many documented complaints, so including a carbon copy to state regulators and politicians of any contested correspondence is appropriate.
- Complain to the accrediting organization. Because HMOs rely so strongly on their accreditation by the non-governmental organizations (NCQA, URAC and JCAHO) in their marketing to employers and unions, they dislike having complaints documented to those groups even less than they like having complaints on file with government regulators. In addition to copying your documentation to the state regulators, copy it to the accrediting organization or organizations that your HMO is a member of.
- Find allies in the medical profession. When medical experts advocate care, HMOs find it harder to deny treatment. Insist on a second or third opinion--from a qualified professional outside the HMO network, if necessary. If your HMO won't pay for a second opinion, pay out of your own pocket. It could save your life.
- Ask how your doctor is paid. Under new rules, Medicare recipients are entitled to see a summary of their physician's contract with their HMO, which details any financial incentives to withhold treatment. Many states now also provide that such information must be given to plan members, if requested. Ask for it. Doctors should increasingly provide such information to all patients. File a complaint with your state's medical board if you believe your doctor is withholding treatment for his or her own pecuniary gain.
- Never take "no" for an answer. Always ask if there are treatment options available for you other than those the HMO recommends. If you have a problem, take it up the ladder--fast. Enlist the help of your employer's personnel department if you get your health care through your work.
- Never stay in a hospital by yourself. Have a spouse, loved one or friend present at all times when you are in the hospital, even if that means sleeping in a chair. Having an advocate present to monitor what is happening around you, to make sure you get the treatment you need, is essential. If something goes wrong, he or she can act quickly to secure assistance.
- Do not be intimidated. Do not permit yourself to be intimidated by someone else's uniform, occupation, credentials and stature. You're paying the bills, not only as a consumer, but also as a taxpayer who helps fund the medical system. Don't let the bureaucrats slow you down. Write and call everyone you can think of in the HMO--the CEO, the Medical Director, the President of Marketing, the Board of Directors. Contact your elected representatives for help. Write the newspapers. Enlist your doctor as an advocate for you whenever possible (good doctors will put aside any conflicts of interest to protect your health). Enlist your employer if you get your health care through your work.

- But always maintain a reasonable, professional and calm demeanor, both in person and in writing--no matter how hard that is to do sometimes. If you lose control, make threats of violence or use foul language, you will simply be dismissed as a "crank," a "flake" or a "weirdo" and you will not accomplish your goal.
- Get the medical care you need. You must always remember that your health care is your most important priority. Do whatever you have to do to get the medical care you need--mortgage your house, get loans from friends and relatives, try to make deals with the doctors and hospitals, get the community to help with fundraisers, if necessary. But get the care and worry about the money later.
- Get a lawyer if you need one. Lawsuits are no fun. They can take years, involve endless and grueling maneuvering. Most who go through the process say they underestimated how hard it would be, especially to relive the medical trauma. And then, of course, there is the possibility that you have a legitimate case but will be unable to prove it in court, or laws won by the insurance industry may limit your right to even go to court. Nevertheless, legal options are often your only leverage against profit-driven managed care. A medical malpractice suit or a lawsuit for failing to pay claims properly can hit an HMO or insurer where it hurts it the most--the pocketbook.
- If possible, never give up the right to go to court. Avoid signing arbitration agreements that force you into HMO-controlled private justice systems. (Cross out the arbitration clause and initial it; if your employer has signed your right away, lobby to change that provision of the contract.) Also, some insurers require you to file complicated internal complaints before going to court. Follow these instructions exactly, but don't delay in consulting a lawyer in the meantime.

These are only tips. To be an effective advocate for yourself or someone else, there are a host of principles you can follow and many excellent books on the methods of advocacy, including two books by the pioneering insurance bad faith lawyer Bill Shernoff, *Fight Back & Win* (Bottom Line, 1998) and *Payment Refused* (Richard & Steinman, 1986). But here is a primer.

Effective Advocacy

The most effective advocate is the most persuasive. Persuasion is the goal of all advocacy. Persuasion is the goal of the written word, the spoken word, unspoken messages. The right words or action from the right person or people to the key decision-makers at the appropriate time is the equation for success in advocating any position.

A series of small victories at being persuasive equals a successful campaign.

Get the right doctors on your side who will then write to the correct medical director with the appropriate language and you are more likely to get care.

Perhaps one doctor is a stumbling block to you getting appropriate treatment. This physician may have a financial incentive (capitation) not to refer you to a specialist or for a test, because the money for these procedures comes out of the doctor's own pocket. Ironically, in this case, the HMO could be one important ally. If the HMO is not paying for the treatment, since the risk is shouldered by the doctor, the HMO has no disincentive to helping you compel the doctor to provide appropriate care.

Being persuasive starts with forming a strategy. Who is the right decision-maker? What words will most influence them and from whom? How much time should I give them to reply? These questions must be asked before mapping a strategy for action.

Forming A Strategy

Effective advocates do not make a first move without forming a strategy. The first formation of a strategy is a clear identification of your goal and your obstacles. The goal should be as specific as possible, but it may require many goals to achieve a large one.

For instance, receiving a specific course of high-cost treatment may be your goal.

To achieve this you will have to map out much smaller goals.

Each of these smaller goals should have a timeline attached to them, leading up to the large goal. Identify potential allies as well as obstacles.

Main Goal: Proton-beam therapy to start by January--referral from medical group for out-of-network treatment.

Obstacle: Primary Care Doctor X and His Medical Group Do Not Want To Make Referral Because They Are Responsible For Treatment's Costs But No Qualified Specialist Exists Within Medical Group

Allies: Government regulators; the HMO (it is not paying for the treatment because it passed full risk to the medical group, so it might as well help you get the care); the specialists out-of-network who will provide the care.

Sub-Goals--Map Of Goals

First Goal: Letter From Specialist Physician To Medical Group Medical Director Asking For Treatment, Noting No Qualified Specialist Exists In Medical Group
Timeline: By Tuesday

Second Goal: Official Letter From Patient To Medical Group Asking For Treatment And Requesting A Response By Next Monday
Time Line: Today

Third Goal: File Preliminary Complaint with Regulatory Agency
Timeline: By Wednesday

Fourth Goal: Specialist Physician To Follow-up On Letter With Phone Call To Medical Group Medical Director
Timeline: By End Of Week

Fifth Goal: File Complaint with HMO's Customer Service Department
Timeline: By Wednesday

Sixth Goal: Have HMO Officer Call Medical Group About Treatment
Timeline: By End of Week

By creating a work plan and mapping your strategy, you can chart the advancement or stalling of your strategy and react appropriately. Your strategy map is a formula for what is reasonable. When it runs astray, you should react proportionately.

Achieving The Strategy

Passion is essential to any effective advocacy effort. When a loved one's life and death is at stake, passion tends to enter the equation. But your goals must always be to establish what is reasonable and not let your anger fog the vision of what needs to be done or keep potential allies from helping you. That is not to say that you should not communicate the urgency of the situation with every contact you make. You should. But you must be under control and maintain good human relationships. You should cultivate allies, rather than simply making enemies. Keep your dignity and composure even as you communicate a sense of urgency about the life and death stakes of the situation.

Consider the situation of Harry Christie, whose daughter Carley was stricken with a rare cancer called Wilms tumor and his HMO would not approve a surgeon who had performed the removal procedure before to do the job. (Chapter One) The Christies made a decision on the spot to have the care rendered and worry about payment later. Today, Carley is living a happy and healthy life as a result. Harry's strategy was then to go through every step of the process and get all the allies he could to force the HMO to pay for the care and be punished for their denial. While passionate, Harry's calm and deliberate demeanor, skills he had cultivated in the electronics industry, led to the state of California ultimately fining his HMO--Takecare, later FHP--\$500,000 for its failure to approve the proper surgeon. Harry fought a three-year battle and only because he cultivated an employee in the state regulator's office who knew the system did he ultimately get justice for his daughter. Harry's strategy was to patiently do everything possible to reach his desire to hold the HMO accountable. His initial decision to make certain that his daughter received the care she needed without waiting for the HMO's approval was a wise strategic choice to put her health above the HMO's rules.

Harry's advice is "I thought I had approval the night before the surgery. Then they back-peddled and said we didn't seek pre-approval. That is a falsehood. Then it took eleven months to recover the medical bills. Next time I would have gone directly to the medical group. I thought I had to do all my

dealings through the managed care plan. What I didn't know was that the medical group held its own set of cards. If you know in your heart of hearts what you are being told is not right, you have got to go with your instincts and do what needs to be done and fight it afterwards."

In dealing with a difficult medical situation, a balance of passion and reason is essential. It will also help keep key decision-makers to deadlines.

It is your job as a patient's advocate to set those deadlines for the key decision-makers.

Patient Advocate: We sent you the medical records Thursday, I am just following up to make sure you received them so you can issue the approval for my sister's treatment. As you probably know, she is in much pain and, as the letter attached to her medical records indicates, she must receive this treatment immediately.

Administrator: I have received the paperwork, but it is going to take a little while to process. The medical director has not yet reviewed it. I do not know that he has everything he needs to make a decision. But we will call you as soon as he reviews it.

Patient Advocate: What is the name of the medical director who is making this decision?

Administrator: It will either be Doctor Green or Doctor Yellow.

Patient Advocate: How soon will Doctor Green or Doctor Yellow be reviewing the file?

Administrator: I cannot say. We understand the urgency of the situation and will do this as soon as possible.

Patient Advocate: My sister is in so much pain. I need to give her a timeframe. What is your deadline for making this decision?

Administrator: I am certain they will look at the files this week, but they may need additional information, or to talk to the doctors involved. They will certainly begin the process this week. If they have everything they need, I am sure the decision will be made soon.

Patient Advocate: May I speak to Doctor Yellow or Doctor Green?

Administrator: They are not available. They are in a meeting. They will get to your sister's file as soon as they can ma'am. Please be patient.

Patient Advocate: I understand you are all very busy. I just would like a timeline for this decision so I can talk with my sister about her options. You understand, don't you?

Administrator: Of course.

Patient Advocate: Can you give me a timeline?

Administrator: I am sorry, ma'am. I can't.

Patient Advocate: I am sorry, your name was Debbie _____.

Administrator: Debbie Red.

Patient Advocate: And who is your Supervisor?

Administrator: Dr. Orange.

Patient Advocate: And who is Doctor Yellow and Doctor Green's Supervisor?

Administrator: Dr. Orange.

Patient Advocate: Is Dr. Orange available?

Administrator: Let me transfer you to his Secretary.

Patient Advocate: Before you do that, will you please leave a message for Doctor Green or Doctor Yellow, whichever will take care of this file, to call me.

Administrator: Yes, ma'am. I have your number. Let me transfer you to Doctor Orange's office.

"Pinning" is the art of getting a timeframe for a decision and working through the hierarchy in this or any other organization. To pin is to narrow a commitment, a timeframe, a decision. You pin someone down to either get a commitment or more information that will lead to a commitment from a decision-maker. It is especially helpful in this scenario to know what the timelines are that are established by the appropriate state regulations or the applicable accrediting organization. Communicate to the administrator that you know what those timelines are and that you expect them to be complied with.

The commitment is, of course, the goal of what you are pinning for but in some conversations it will be impossible to get a commitment because you are not speaking to a decision-maker.

Finding the chain of command and utilizing it is the modus operandi of pinning down a decision in the corporation. You must remember who you are talking to and what the purpose of your conversation is. The so-called administrator in the above example was not a decision-maker, but an "informer"--someone who could landscape how the company worked and what the chain of authority was. It would make no sense to argue with this employee about the details of the patient's condition, coverage or state law's requirements about covering the patient's condition. The purpose of this conversation was to find out who to write the letter detailing these facts to and putting the best case forward.

Know who you are talking to at an HMO. It makes no sense to argue your case before a bailiff, you must find the judge.

Sizing up an employee means a persistent but friendly conversation--pushing the limits of the conversation as far as they go, and gathering information. Persistence is the key to effective information gathering and pinning. Most people, however, are uncomfortable pushing the cusp of a conversation beyond what may be considered good manners. These are inhibitions which must be forgotten when an HMO acts unreasonably and jeopardizes a patient's health.

Chain of Command

"You never expected justice from a company, did you?" asked 19th century English writer and clergyman Sydney Smith. "They neither have a soul to lose, nor a body to kick."

But in every corporation there are people. People can be persuaded.

Every hierarchy has a chain of command. HMOs are nothing if not hierarchies. If a customer service representative cannot help you, talk to their supervisor immediately. If the supervisor cannot assist in the timeframe necessary, contact their boss, the division head, the medical director, the chief executive officer. Go as far up the chain of command as fast as possible. People make decisions most effectively when they feel that making the wrong decision will jeopardize their position. HMO values may not encourage compassion. But no HMO personnel wants a written record that they have blood on their hands.

Every fight with an HMO for receiving patient care today is a fight for whether civil society and medical ethics will succeed in reasserting itself against HMO and corporate values. The documentation, research and advocacy you contribute to this process can help change things for the better for others. When all else fails, or does not appear to be succeeding in time, enlist others who can help even the balance of power between the patient and the corporation, such as the media. The level of what is reasonable that you help to establish for yourself or loved one will help clear access to care for those in the future.

For Medicare recipients, an internal appeal by an HMO must be reviewed and answered within thirty days. An expedited appeal should take seventy-two hours if the patient has a problem that could seriously jeopardize life or health or the ability to regain maximum function. If the HMO turns down the first appeal, an individual can ask for a reconsideration, and the health plan must answer within another thirty days, or seventy-two hours for an expedited appeal. If the appeal is rejected again, the HMO must send the case for independent review to the Center for Health Dispute Resolution, located at 1 Fishers Road (second floor), Pittsford, NY 14534. The center can be reached at (716) 586-1770.

ADDITIONAL RESOURCES

HMO Regulatory Agency – California:

Department of Corporations
980 9th Street, Suite #500
Sacramento, CA 95814-3860
916-445-7205
Consumer Services Unit
800-400-0815

Books:

Making A Killing: HMOs and the Threat To Your Health.
Jaime Court. 1999. 229 pages.

Don't Let Your HMO Kill You: How to Wake Up Your Doctor, Take Control of Your Health, and Make Managed Care Work for You
Jason Theodosakis, David T. Feinberg. 2000. 334 pages.

Fight Back and Win: How to Get Hmo's and Health Insurance to Pay Up
William M. Shernoff. 1998. 156 pages.

Managed Dying - An HMO Survival Guide
Barbara Johanna Janesick, Luis O. Garcia, Karon L. Goldsmith. 2000. 164 pages

Outsmarting Managed Care: A Doctor Shares His Insider's Secrets to Getting the Health Care You Want
Bruce A. Barron. 1999. 288 pages.

The Insider's Guide to HMOs: How to Navigate the Managed-Care System and Get the Health Care You Deserve
Alan J. Steinberg. 1997. 256 pages.

TCN Publications:

California "Duty of Ordinary Care" – HMO Accountability Act

California Pain Patient's Bill of Rights

California Patient Right To Access Medical Records