PATIENT POWERline from the desk of Marie Savard, M.D.

RE: Part Two of Dr. Susan Lark's Newsletter, "The Lark Letter"

Dear Friends,

Last month I shared with you the first part of my discussion on gaining control of your health and medical records that was published in Dr. Susan Lark's newsletter, "The Lark Letter". The following is part two of that discussion and is published in the September 2003 issue.

MEDICAL RECORD COLLECTION 101 – ON THE JOURNEY TO PATIENT POWER

NO ONE HAS A COMPLETE SET OF YOUR MEDICAL RECORDS

Last month I shared with you my thoughts about why you need to be in charge of your health information. I would now like to show you how to do just that. Remember, the days when a family doctor had all your medical information in a manila folder, at the ready day and night, are long gone. In all likelihood your records exist piecemeal in an array of offices, computers, laboratories, and microfilm at one or more hospitals. If you've moved around a lot, it's a pretty sure bet your records didn't follow you. To be safe, you need to locate as many of them as possible and keep a set of copies where you can get at it anytime you want.

I know that the idea of figuring out where the paperwork is and trying to collect it – much less understand it – sounds overwhelming, but in the end, you'll be glad you made the effort. The story that I shared with you about my dad last month underscores one important reason. I hope you won't wait until a crisis occurs to try to cobble together the information that could save your life. The last thing you need when you're sick and frightened is to have to think straight enough to remember where your old mammograms might be or what the names of your medications are. Far better to take the time and trouble to get your medical affairs in order right away and keep them up to date from now on. Consider this a kind of insurance that is guaranteed to pay out. After all, you fork over plenty for protection against such things as fires and natural disasters and theft, which may never happen. Why not spend a nominal amount of money and a little of your time to protect yourself against the very real possibility of medical mishaps?

Another reason for gathering your records is that you may find errors, which could cost your insurance coverage, employment, or – in the case of allergic reactions – your life. In this electronic age, a lot of people are looking at your files. Even though your records shouldn't be released or transferred without your signature, information often beams through cyberspace unchecked. Recently enforced federal privacy protections do little more than create bureaucratic headaches for everyone involved and do not necessarily protect your information. Finally, if you don't collect your records yourself, they could be destroyed after two to seven years by the people and facilities that own them. Without a doubt, getting your hands on your records and those of your family as soon as you can

is the only way to have both the power and peace of mind when it comes to your health care.

People often ask whether they are entitled to their medical records, thinking maybe only the doctor or hospital can have that information. Legally and ethically you are entitled to copies of the information in your medical record. In some states, there are laws spelling out patients' rights to their health information and how much patients can be charged. However there is no state that has a law saying you can't have your records. Federal privacy laws include a section that emphasizes the fact that patients can not only have copies of their medical records if they ask, they can even suggest changes or corrections when and if it is appropriate. Remember, the original documents are owned variously by health care practitioners, hospitals and laboratories but you can get photocopies. Note: You can also get copies of the records of your minor children. If you are responsible for anyone else – an aging parent, a developmentally delayed sibling, a grandchild or unrelated child you have taken into your home – you must get legal power of attorney in order to access the person's medical records – or for that matter, to help make medical decisions for that person.

START YOUR COLLECTION THE EASY WAY

Before you attempt to find old medical records, start your collection the easy way. Beginning with your next office visit, request your results and summaries. Give your doctor a self- addressed stamped envelope and a sticky note with the current date, the records you want sent to you, your name in block letters, your signature, and your date of birth. He can then put the sticky note as a flag on your chart to remind him to follow through. Make a couple of sticky notes for yourself and put them wherever they'll job your memory – as a flag in your daily agenda, on the refrigerator, or on your calendar. If you don't receive your results within three weeks, make a follow-up phone call. Get the results of every test and procedure as they occur in the future.

But I can almost hear you saying that you're worried that asking for your records might antagonize your doctor. To be honest, that's not an unfounded fear. Historically, the two reasons a patient might ask for her records were because she was going to switch doctors or because she wanted to get a second opinion. Your doctor is only human, and knowing that you may be questioning his judgment can create a rift in your relationship with him.

This is not to say you shouldn't switch doctors or get a second opinion. Just make sure your doctor understands that your motive right now is simply to get a set of records for yourself so you can work as a team with him and reduce the risk of medical mistakes. When you have access to your own records and come to office visits with a reasonably complete set, it helps your doctor do a better job.

WHO HAS YOUR MEDICAL RECORDS

When you decide to locate your existing records, work in reverse chronological order. What I mean is that you shouldn't let yourself be stymied by the potentially impossible quest for long-lost records. First, let all your doctors and practitioners know what you are trying to accomplish by writing a brief courteous letter to each person or facility who might have what you need. (I have a sample letter on my website at www.drsavard.com

that you can download for free to help you.) Let's have a look at where your records might be.

- I. Your family doctor (and gynecologist) should have the following:
 - a. Progress notes including a running record of your height, weight, and blood pressure. (The handwritten notes are not particularly helpfully so don't request them.)
 - b. Typed summaries dictated by specialist you've seen such as cardiologists or urologists.
 - c. Discharge summaries from hospital stays and emergency room treatment.
 - d. Results of all blood work and urinalysis.
 - e. Pathology reports (Pap tests, biopsies).
 - f. Radiologists' reports (chest x-rays, mammograms, bone density scans). (While you're at it you might consider getting a copy of the actual x-ray pictures along with the typed reports. This is especially important for women who move and need to have mammograms read and compared at another facility.)
 - g. Results of heart testing (EKG, cardiac stress test, cardiac echo).
 - h. Results of screening and diagnostic tests (allergy testing, colonoscopy).
 - i. Your doctor may also have your immunization history. If not, blood tests can determine which antibodies you have if that ever becomes important.
- II. In the event that your family doctor does not have consultation reports, which should have been sent to him by specialists, contact the specialists directly. Also if you regularly see a specialist such as a cardiologist, make a habit of getting your results on an ongoing basis just as you do when you visit your family doctor of gynecologist.
- III. In the event your family doctor does not have hospital discharge summaries, contact the medical record department at the hospital and specifically request the summary. Otherwise you may get (and be charged for) the whole file, which will be redundant and probably include scribbled notes you would have trouble reading.
- IV. In the event that your family doctor does not have laboratory results (Pap tests, biopsies, blood work) or radiologists' x-ray reports (chest, mammogram or bone density scan), you can try contacting the lab or hospital radiology department. This may or may not work, but it is worth a try. You have probably heard that a good ploy for getting the hospital to release your records is to have a doctor friend request them for you even though your signature is required to get them. But I'm against game playing, which only perpetuates the model of the powerless patient. There is strength in numbers, and if we all start to ask what is rightfully ours, giving patients copies of their records will become commonplace.
- V. Contact complementary care clinicians (acupuncturists, physical therapists, chiropractors).

Be sure to give your date of birth in all correspondence about your medical records and the medical record number (located on all x-ray reports) if you have it. You can send a letter with a self-addressed stamped envelope included, or you can request that your records to faxed to your personal fax machine. In any case, you should send a check to cover the cost of copying your records. I'd offer from \$10.00 to \$20.00 depending on

how many records you're requesting. Many states have laws in place noting how much a facility can charge to copy each page from your record. Be specific about which records you want or you may get a sheaf of useless, scribbled notes along with the typed reports and summaries. Whether or not your doctor accepts the money, she'll appreciate the offer. In a sense, it is the thought that counts.

But what if you don't get your records in spite of the pleasant tone of your letter? I'd give the doctor or facility three weeks to act on your request, and then I'd place a follow-up phone call. You will probably feel annoyed, but avoid being confrontational. If the office staff tells you that it's not the doctor's policy to send patients copies of their records, don't let yourself be intimidated. Be polite and persistent – remind them it is not only your legal right – the information may be critical to future doctors involved in your care. Remind the office staff that legally you have a right to this information no matter where you live.

CARRY A LIFESAVER WITH YOU

Make a personal health information list to carry with you at all times. Tuck it in your wallet with your health insurance information and give a copy to all your treating practitioners. (If my dad had a health information list with him when he presented to the hospital with a near-fatal heart arrhythmia, his doctors would have suspected the offending medication, Digoxin, and begun emergency treatment.) Include the following information: list of medical conditions (e.g., hypertension, diabetes, osteoporosis, heart murmur requiring antibiotics before dental work); serious adverse reactions to medication, bee stings, seafood, x-ray dye; an up-to-date list of medications, vitamins and herbal supplements including dose and directions; significant family conditions; most recent immunizations for tetanus, flu and pneumonia; and living will information. My dad now carries a lifesaver with him at all times and has shown it to every doctor, pharmacist and practitioner he sees. (You can download a free health-at-a-glance form from my website at http://www.drsavard.com)

Now that you have learned to collect your own medical records, you can learn to read them as well along your path to become as informed a health care consumer as possible. This is not as formidable undertaking as it might sound. In fact, your foray into medicine will demystify aspects of your care that once seemed like scary mumbo-jumbo. I will come back sometime soon to guide you and help you gain the medical knowledge that will let you be confident, aware, and in control. That kind of power, in an era of ever-increasing depersonalization and fragmentation in our health care system is nothing short of revolutionary.

As an ancient proverb put it, "A journey of a thousand miles begins with a single step." By collecting your medical records you have taken the first step on the journey to save your own life.

Warm regards, Marie Savard, MD

To learn more about Dr. Savard's health management system, download free forms and a sample letter to your doctor, or to order her books How To Save Your Own Life: The Savard System for managing – and controlling – your health care (Warner Books, Inc.

2000) and/or The Savard Health Record: a six-step system for managing your health care (Time Life Books), visit http://www.drsavard.com.

By using the information and forms, in "The Savard Health Record", you will learn to how to prepare for office visits, set your target goals, collect and read your medical records and understand your test results. In short – you'll have everything you need to manage your health care right at your fingertips.

Marie Savard, M.D. is an internationally known internist, women's health expert and champion of patient empowerment. She is the founder of The Savard System, dedicated to teaching patients how to manage their own healthcare. She is the author of two highly acclaimed books, How to Save Your Life: The Savard System for Managing-and Controlling-Your Health Care (Warner Books, Inc. 2000) and The Savard Health Record: a Six-Step System for Managing Your Health Care (Time-Life, Inc. 2000).

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