

# Obtaining and Storing Your Personal Medical Records

By Jim Wong, PhD



As patients with congenital heart defects (CHD), the detailed information about our defects, surgical procedures, and tests are critically important for accurate treatment by our health care professionals. The majority of our older records are xeroxed or faded carbon copies stored in manila folders, which are locked away in long-forgotten hospital or doctors' filing cabinets. Unfortunately, these one-of-a-kind records are subject to damage, loss, or theft. It seems like every month someone on the Adult Congenital Heart Association (ACHA) online Message Board tells a story of how their childhood medical records are unobtainable due to their pediatrician retiring, the hospital closing, or the records just plain being lost or misfiled. While there is little that can be done about those old records, it is well within our power as knowledgeable patients today to obtain and keep excellent records of our recent diagnoses, tests, and procedures.

Many people know that the Health Insurance Portability and Accountability Act (HIPAA) of 1996 guarantees access to health insurance for a period of time after leaving a job. But perhaps equally important is the "privacy rule" that, besides protecting the privacy of our medical information, also gives us the right to view and obtain copies of our own medical records and to have corrections added to any records that we believe to be in error. With this law on our side, we can obtain, compile, organize, and analyze our medical records to our hearts' content (no pun intended).

To get copies of the medical records, one must often fill out a form at the hospital, clinic, or doctor's office, and pay a nominal fee for copying and mailing the records. Fees for photocopying (usually about 25¢ per page), postage, and handling are common when records are sent to a patient. However, these fees are often waived when sent to another doctor or hospital, such as your primary care physician, who may be willing to provide these records to you at no cost.

Once you have your records, what is the best way to keep them safe and secure? First and foremost, one should put the copies into a three-ring binder or paste them into a

composition book to keep them organized and in a single place in your home. If you have periodic tests, it may be useful to make a table of key measurements so that you can look for long term changes in your results. For example, a tetralogy of Fallot patient may track his/her QRS duration from the EKG. These paper records are still vulnerable to loss due to fire, theft, flooding, etc., so it may be a good idea to keep an extra copy at a loved one's home or in a safety deposit box.

Since we are living in the information age, we can avoid the possible loss of hard copies by using our computers to store our records in digital format. With a common scanner, you can create digital images of your hardcopy records and store them as files on your personal computer, external hard drive, or USB flash drive. If they are stored as Adobe Portable Document Format® (PDF) files, they will be readable on almost any computer. If your scanner program does not come with a way of saving the image in PDF format, you can always use a free program such as Cute PDF ([www.cutepdf.com](http://www.cutepdf.com)).

## Did You Know?

- You have the right to receive and review all your medical records.
- You can often avoid per-page charges by asking your doctor to request health records for you. S/he can give you a free copy when s/he receives them.
- There are now many tools available to store health information on the Internet.

Carrying a summary of your critical medical records may be life-saving in a medical emergency. A copy of your latest surgery report, a list of all medications and

dosages, and your most recent electrocardiogram are critical information for an emergency room doctor. This small, capsule summary can easily be stored on a low-cost USB flash drive and kept on a keychain or in a purse.

An alternative method to ensure safe, secure access to your medical records is to store them on a “personal health record” (PHR), accessible over the Internet, just like your bank or brokerage records. Some of these electronic PHRs can be securely accessed by medical providers, emergency room doctors, or EMTs. This quick access to your critical medical records will allow the medical professional to understand your health condition and devise an appropriate course of action. Some health insurers and clinics are providing them at no cost to their customers. An example is the partnership between the

Cleveland Clinic and Google to test the “Google Health” PHR with their patients. If you are not a patient of the Cleveland Clinic, there are alternative PHRs available for your use. Here are descriptions of three of them:

#### **ACHA's online Personal Health Passport**

Accessible at [https://www.achaheart.org/for\\_members/health\\_passport.php](https://www.achaheart.org/for_members/health_passport.php) this online Personal Health Passport allows you to electronically and securely store the information contained in your hardcopy Personal Health Passport. The only exceptions are that the electronic heart diagram cannot be modified and test records cannot be uploaded. However, the addition of those features is currently being assessed. Data stored online is accessible to you via the Internet whenever and wherever you are logged in.

#### **Personal Health Record with a Standard Membership to MedicAlert®**

MedicAlert® is a nonprofit organization that provides medical pendants and bracelets. Once you provide them with your detailed diagnosis; contact information for yourself, your emergency contacts, and doctors; and other health data, all of this information will be available to emergency health workers over the phone and to you over the Internet. This PHR can only hold basic health information as allowed in their online forms.

#### **MedicAlert Gold Program**

Available at [www.medicalert.org/Gold](http://www.medicalert.org/Gold) this \$9.95 per month premium service allows you to store and organize all your medical records online. Members receive a personal fax number to which either they or their health professionals

### *Tips for Taking Charge of Your Records*

- Keep copies of all your important cardiology records. Most important are surgical reports and results of diagnostic tests.
- Request copies of any missing important health records now. By planning ahead, you will avoid trying to find information during a health crisis.
- Ask your cardiologist's office to automatically send you a copy of all test results and letters.
- Store your paper records in a three-ring binder. Tab the binder so that the most important information is easy to find quickly.
- Consider copying your information onto a USB flash drive. Carry this with you so you can access information wherever you are.

can fax their medical records, images, and test results. From there, the information will be digitized, converted to PDF files when appropriate, encrypted, and stored securely on servers in an enterprise-level data center. One can also log on via the Internet, upload additional files, and organize the information in folders for ease of use. This service is provided by a partnership [www.MyMedicalRecords.com](http://www.MyMedicalRecords.com), who stores the data on multiple servers more than 100 miles apart with redundant access to improve availability and accessibility to your online medical records and protection against loss in the event of natural disaster.

Many more companies are working to provide online personal health records, and we will continue to see additional partnerships between medical institutions, insurers, and high tech companies like Microsoft and Google.

There are many ways to store your medical records once you get them from your health care provider. It is a good idea to get them now and organize them in a manner that works for you, in advance of any emergency situation. ■