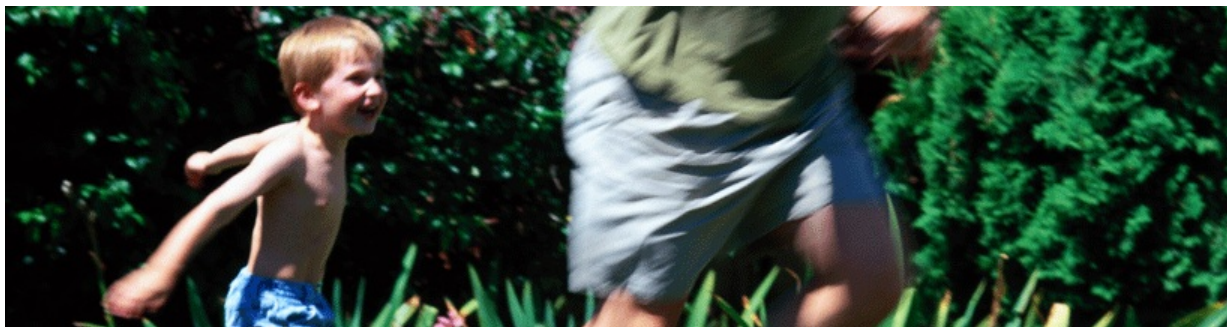




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## Your Health Records: Why and How to Access, Organize and Use Them

*By Leslie Levine*

As a neuropathy patient, you probably have seen multiple physicians and other care providers. Whenever you have an appointment, you are asked to provide information, and the provider's findings and conclusions, as well as new test results, are added to your growing medical records. You may well have multiple sets of records, one for each hospital system or provider group. While the task may seem daunting, you may want to consider obtaining your records and putting the information into a format that will be very helpful in getting you the best medical care as efficiently and cost effectively as possible.

Why should you do this? If you know what is in your medical record, you will be able to understand your health history and be your own best advocate. You'll be able to ask better questions, and work better with your providers to make decisions. You can track your lab results and

July 2018

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Thank you to all who joined us in Los Angeles on June 22 at the Intercontinental Hotel for the 12th Annual "Neuropathy Action Awareness Day." A very special thank you to our sponsors and exhibitors who made this event possible.

This year over 1,500 patients, caregivers and others attended the event in person or virtually using the latest live streaming technology. A few highlights include:



Special thanks to expert panelists **Francy Shu, MD**, **Jeffrey Ralph, MD** and **Said R. Beydoun, MD** for participating in "Ask the Experts".



Congratulations to **Bev Anderson (R)**, President/Founder of the Western Neuropathy Association, who was awarded the "You Are Our Hero Award".



Special thanks to our sponsors and exhibitors who helped make the 12th Annual NAAD possible.



12th Annual Neuropathy Action Awareness Day a huge success!

medications. Each healthcare provider you see wants to know your medical history, but does not have time to read through hundreds of pages of medical notes and lab test results. They rely on you to summarize what you know about your medical condition(s), what testing has been done, test results and the conclusions of other providers you have seen. Few people can accurately recall the details of their medical visits and testing, and frequently the provider only shares part of his or her thoughts and concerns with each patient. In the few minutes allotted for the initial patient - doctor conversation, some material may be misunderstood or entered in your record inaccurately. The only way for you to be sure that your providers know your past medical history, so they can partner with you to give you the best care, is for you to get your records, check them for accuracy, organize the contents into a usable format, and share this summary with your medical care team. Your efforts will be welcomed by your team of providers, especially new ones trying to get up to speed.

What does this involve? First, you need to get the complete record from each of your providers and hospital systems. You have the right, under the Health Insurance Portability and Accountability Act, or "HIPAA", to see and get copies of all your health records. While some providers have website portals where you can access some of your test results and certain other materials, these almost never include all the information that is in your full medical record. Typically you need to request your records in writing. Most providers will give you a records release form either by request or available on their websites. You will need to complete the release forms, designating yourself as the one to whom the records should go, and mail or fax it back. The release form will ask the purpose for which you want your reco

If you missed the event or would like to watch it again please [CLICK HERE](#). The entire day was recorded so you can watch online at your leisure.

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## Never Give Up!

### *Multifocal Motor Neuropathy (MMN) Patient Story by Gary Croll*

My name is Gary Croll and I am 66 years old. My story starts as a teenager when my hands started locking up & I wasn't able to release objects I was holding. Our family doctor, (a DO), was the only medical help available to me and eventually the problem subsided on it's own. I was aware at even that young age there was a problem because I had an awkward gait and tended to fall easily.

Fast forward to the mid 70's, I'm married, working and starting to have the locking problem again. I went to a neurologist, had the nerve conduction studies done, was hospitalized a week for testing, and the diagnosis, I'm "wired wrong".

Years later I was living in California and was having problems again and started seeing a neurologist for hand locking, headaches, balance issues, etc. The diagnosis, I'm "wired wrong".

Now we're in the early 2000's, I'm in Arizona and the same problems are starting again. There are 3 neurologists in our town & I've seen 2 of them. They did their testing, physical exam, EMG, (nerve conduction), muscle biopsy, etc. The diagnosis, I'm "wired wrong". By now I have found an extremely good internal medicine doctor who has taken a personal interest in my case. It turns out I am a type 2 diabetic with some peripheral neuropathy. I also told him of my neurological issues and he referred me to the 3rd neurologist in town.

In 2017 I began seeing my current neurologist. My most recent neurologist had forwarded him my file. On my first visit, he seemed very confused saying he didn't expect to see me walking into his office. He said typically, patients with EMGs like mine weren't able to walk. He did a thorough exam & repeated the EMGs. By now I was also having contracture of the right hand, muscle atrophy, and more balance issues. I had hand surgery in March, (no help), followed up by 8 months of physical & occupational therapy, (also no help). By now my neurologist had made the diagnosis that I had CMT, Charcot - Marie - Tooth), disease, a degenerative neuro - muscular disease in the MD family. As I did the research on CMT, I was devastated, no treatment, no cure, no hope.

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## Importance of A Knowledgeable Neurologist

rds. Since you are using the information to provide to your care team, you should mark the reason as being for medical care; this often will incur no charge for the records. Be sure to request your entire medical record, including providers' notes about visits, discharge summaries, reports on labs, operations, pathology, radiology, genetic screening and mental health care reports. You can also request information on your account and billing history. The law requires that you be provided with your medical records even if you may still owe medical bills. You will usually be able to choose the format in which you get your records. If you request your records in paper form, there may be a per page fee. The fee is typically less, or even free, if you request that your records be provided electronically by secure download. There may be an additional fee if you want copies of photographs or x-rays along with your records. The provider has 30 days to send you your records, but often will provide them in less time.

Now that you have your records, what next? You might want to get sets of file folders, and separate the records into sections, such as for visit notes, hospital inpatient stays and discharge reports, lab tests, radiology/imaging reports, cardiology, pathology, microbiology and other tests (like neurophysiology testing such as nerve conduction velocity or autonomic function testing). The records will typically be in chronological order. As you go through the records, be sure to note if you think there is an error. You would then ask your provider to correct the record. Even if the provider disagrees with you, you have a right to have the facts of the problematic material put into your medical record.

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### *Multifocal Motor Neuropathy (MMN) Patient Story by Diane Punzo*

I often go online to see if there is anything new on Multifocal Motor Neuropathy (MMN). I was lucky enough to come across the GBS/CIPD Foundation International and the Neuropathy Action Foundation (NAF). I explained to them my very long search for information, many doctors, many tests, useless surgeries (two ulnar nerves) starting in 1986 for an answer to my issues with my hands cramping and shaking and was finally diagnosed with MMN in 1991.

I looked up the NAF Founder's video who also has MMN and was so moved by his video on Plasma Donors, I never thought about it like that - very moving! I have never met or spoke to anyone with this disease. I am so used to trying to explain this disease to my friends.

Since 1989 I was diagnosed with many diseases, called crazy, and told they thought I had ALS. I live in Biloxi, MS and saw all the neurologists in this area, sent to New Orleans LSU and Tulane. I was lucky enough for my chart to be sent to Dr. Appel in Houston in 1996. After three long days of tests he came in and said I have good news and bad news. The good news was that I did not have ALS (due to spinal tap and muscle biopsy) and the bad news is that I have MMN and there is no cure.

Within a month I was in Houston again doing rounds of IVIG, Rituxium, plasmapheresis, and Cytoxan. Which I continued back home for many months. For a couple of years, I continued to drive to Houston for check-ups. I felt that Dr Appel was happy with me and I felt he was done with me. Most of his patients had ALS. A doctor in Biloxi picked me up and sent me to a new neurologist in our area. Dr. Bowen, who I love! He did some research and sent my records to Dr. Pestronk in St Louis, MO. By this time, it was 2004. I have been receiving IVIG every two weeks and several rounds of Rituxium (which I just finished my two year-round). I currently see Dr Pestronk in St Louis two times a year and monthly visits to my hometown Dr Bowen. I tell people that if you ever feel not right about a doctor's diagnosis to keep looking!

Since 1988 I have lost the movement in my left thumb, have very weak fingers and atrophy. I was 30 when this started and am now 66. I had to switch well paid jobs for entry level jobs to just have insurance. I was very lucky that I had long term disability and had to leave again a very good job (I could not do the hand work necessary in management at a local casino). I applied for Social Security Disability, which took me three years to get approved. I am VERY lucky now that I have Social Security and a second policy. I never had to pay one cent for care.

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