

All-In-One Insurance Coverage - USA

Unlike traditional health insurance companies, organizations like Humana and Kaiser own their hospitals, imaging facilities, pharmacies, and employ doctors, nurses, etc. They appear to diagnosis and treat 99.9% of all illnesses and diseases very effectively, and it's quite efficient if an MRI, a CT or x-ray is ordered, it's just a matter of going downstairs, having the imaging done, and then going back upstairs to review the results with your doctor.

Given they own the hospitals and employ this staff, companies like Kaiser and Humana are often extremely reluctant to refer out-of-network and pay non-employee physicians: they refer internally to an employee doctor/specialist who is already on their payroll, which makes sense 99.9% of the time. Referring internally basically costs them nothing extra, while referring externally is expensive and requires heightened levels of executive management approvals.

That said: when it comes to extremely rare diseases, there is very little expertise outside of large multidisciplinary cancer centers; maybe only a dozen in the US. It's imperative that patients and their advocates **learn as much as possible** about their rare disease so they **can make informed decisions**. Some surgeons or oncologists may have heard of an extremely rare disease by name, but very few can effectively diagnose or properly treat extremely rare diseases such as chordoma, Ewing's sarcoma, etc.: these are not cookie-cutter cancers, and required absolute expertise

If an MRI implies or a biopsy concludes a very rare disease, patients can go to their Patient Records (or "Release of Information") department and have the associated **imaging** and **pathology** reports **copied to a CD**, about \$15 per CD; and request multiple copies. This isn't to imply you must have a biopsy done, but most often only experts who diagnosis and treat them routinely can determine that a tumor or mass is highly likely to be something extremely rare, or highly unlikely to be something so rare from an MRI. Only a rare disease expert should order a biopsy. The Patient Records/Release of Information department will often tell you it will take 2-3 business days to create a CD, but it only takes about 30 minutes). Very nicely and gently explain that you have been diagnosed with an extremely rare form of cancer, and that experts are awaiting the imaging for an urgent second opinion. (Don't leave it up your doctor to send it)

Write a brief summary about yourself and include symptoms, for example:

- Healthy male, age 50, 6' tall, 180 pounds, relatively active, non-smoker, no history of diabetes, no heart disease, or family members with a history of cancer. Include...
- **First symptoms** in May 2017, very sore tailbone suspected from a fall, with numbness starting in my right thigh. Over the next X months, pain and numbness traveled down my leg. The pain gradually increased over time and I am taking 10MG of pain med (by name) every 4-6 hours. **Imaging or testing** to-date: MRI (if any) with the report taken on Feb 15, 2018: report was inconclusive, suspected X (X = name of disease/findings on the report). Pathology if any: have that report printed for you, and/or burned on the same CD that contain the MRI

Lessons learned:

- **Out of Network Referrals:** They're often very slow to fund non-employee doctors for second opinions or actual treatment. Contact your rare disease patient navigators or online peer groups to determine rare disease experts (plural) nearest to you. Get multiple second opinions by experts
- **Don't wait** for an official out-of-network referral: they can be a nightmare of management approvals. **Do** contact the office of the external experts directly. Summarize the suspected diagnosis, and ask them if you can mail imaging on a CD with a brief synopsis so the doctor can review your case, then ideally discuss with you on the phone. (There may or may not be a cost, but the cost of an initial consultation is often nominal, if anything)
- The importance of **patient education is imperative** to ask the proper questions and make **informed decisions**
- Non-rare disease experts make be outstanding surgeons, but most don't know what they don't know
- Be sensitive -not- to appear insulting to your assigned PCP. When requesting out-of-network consults, suggest that you're not saying "not you", you're simply saying "not yet, this is a very complex disease to treat, would you agree?"
- Once you've had expert consultations and understand your disease, **lead your PCP** towards the solution that is best for you with questions like: "given the extremely rare nature of my disease, doesn't it make sense that I should have treatment by an expert multidisciplinary team who treats it routinely?"
- Be prepared with **written questions in advance**, and **bring someone with you** for support and to take notes