How to Navigate Insurance Challenges

Many of us have not had to deal with major health issues or the insurance challenges that come with them until our CCS diagnosis. These tips can help you work more effectively with your insurance company and reduce the time, stress, and frustration involved. Though the tips and resources listed here are primarily for patients in the United States, those residing outside the U.S. may be able to find similar resources in their own country.

1. **Know Your Insurance Company:**
   - Request your Summary Plan Description (SPD), which outlines what's covered/excluded, authorization requirements, the appeals process, and much more.
   - Because you have an ultra-rare cancer, you can request a Case Manager or Care Navigator, who can help expedite imaging, treatments, surgeries, and medications.
   - If you cannot find a high-volume sarcoma center in-network, ask your case manager/care navigator for a Single Case Agreement (SCA). This allows you to see a specific out-of-network specialist at in-network rates when local expertise is lacking. (See below for helpful wording*.)
   - If you're told you must "fail" a treatment before another is approved, remind them that CCS has no standard of care and no treatment that must fail before trying another.
   - Keep your insurance card with you.
   - Know if your insurance requires pre-authorization for imaging, procedures, or treatments; work with your case manager to reduce the risk of denials.
   - If something is denied, your oncologist can request a Peer-to-Peer review with one of the insurer's physicians.
   - Phrases that help avoid denials and appeals:
     - "Ultra-rare malignancy with no established standard-of-care."
     - "Requires evaluation at a high-volume center."
     - "No equivalent in-network expertise exists."
     - "Requesting medical necessity exception due to disease rarity."
     - "Requesting single-case agreement."
     - "Time-sensitive and clinically urgent."

2. **Collect and save all medical records to speed up authorizations and appeals:**
   - Pathology reports
   - Genomic testing showing your EWSR1-ATF1 (or CREB1) fusion
   - All imaging (CTs, MRIs, PET/CTs) CDs and reports.
   - Tumor Board summaries/recommendations
   - A diary of all visits to physicians, imaging centers, labs, hospitals, and surgery centers.
   - All Explanations of Benefits (EOBs)

3. **The Appeal**
   - Ask for denial reasons in writing.
   - Document all calls.

- Provide supporting documentation (NCCN guidelines lack a CCS specific standard of care. CCS is a soft tissue sarcoma (STS) and NCCN has STS guidelines if that supports your position.
- Escalate to a formal appeal and request an external review if needed.

4. **Resources to help address/overturn denials:**
   - Your state's Department of Insurance
   - Hospital-based financial counselors
   - Hospital social worker or nurse navigator can submit pre-authorizations, file appeals, contact insurers, and request SCAs

5. **If you lose insurance coverage, here are some options:**
   - COBRA: expensive but provides seamless continuity
   - ACA Marketplace Gold plan (often best specialist access)
   - State high-risk pools (rare, but available in some states)
   - State Medicaid
   - Medicare/SSI/SSDI if you meet the Social Security disability definition: https://www.ssa.gov/disability
   - Hospital charity/financial assistance programs

Remember, you're not alone in this journey. Connect with others in the CCS Family Facebook Group, the community can be a great resource and support.