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How to Change Unreasonable Insurance Rules

Tricia's story is like many others trying to make arthritis coverage more affordable

My name is Tricia Mershon, and I live with my family in Corona, California. At the age of 3, my daughter, Rachel, was found to have a dysfunctional immune system. Her tiny body failed to mount a response to infection, and various disease specialists were able to document the phenomenon but unable to pinpoint a cause.

Just before ninth grade, Rachel's fingers curved into a funny "s" shape and looked different than those of anyone else. When she began having pain in her feet, knees and hips, which sometimes made walking difficult, Rachel was promptly referred to rheumatology, and we found the real culprit. At 14, Rachel was diagnosed with juvenile idiopathic (rheumatoid) arthritis. She began aggressive treatment to halt the progression of this insidious disease.

"Copay assistance saved us financially and helped my daughter access the care she desperately needs."



Like many families with loved ones taking a specialty medication, we have relied on copayment assistance to help my daughter access her medicine. Without her biologic, she couldn't be as active as she is today. But when my husband changed jobs, we enrolled in a high-deductible health plan, which has a higher deductible than a traditional plan. Although the monthly premium is lower, you must pay your share before your insurance kicks in. Copay assistance saved us financially and helped my daughter access the care she desperately needs.

Recently, we faced a barrier we'd never experienced before: an accumulator adjustment program. We were using a pharmaceutical copay card, which used to count toward satisfying the deductible. But this year, we discovered that was no longer the case. After filling our first prescription, not one cent of it counted toward our out-of-pocket spending. To add insult to injury, we weren't notified of the change until almost two months into the plan year, and our accumulator adjustment program **ONLY** applies to specialty medications – the most expensive tier in prescription drug plans. With this realization, I immediately deactivated the copay card.

“Accumulator adjustment programs basically render copay assistance worthless. Since the medication is so expensive, benefits would be exhausted within 2-3 months with \$0 counted toward our out-of-pocket spending.”

But that wasn't the end of our story. The pharmacy reactivated our copay card without our knowledge or permission. As a result, we've had to pay additional out-of-pocket. Since there are no generic or biosimilar alternatives to my daughter's biologic, this policy change disallowing copayment assistance from crediting our deductible will cost us \$7,350 more per year, EVERY year!

It's not just the costs of the therapies that are burdensome. The time spent on the phone trying to resolve this has been overwhelming. While trying to keep our daughter stable on this medication, we've had to figure out how to navigate the accumulator adjustment program alone.

“We cannot state forcefully enough how concerned we are about how Rachel will be able to afford her medication once she is an independent adult.”



Rachel, now 21, is a college student. Due to her hard work in high school, she earned the Arthritis Foundation's Winterhoff Scholarship! Over the past several years, we've developed relationships with our legislators, going to Washington, DC, and the state capitol in California, to advocate for those with arthritis. The Arthritis Foundation's training has been invaluable, helping Rachel find her voice to tell her story with confidence.

If your family has an experience that sounds like mine, sharing your story is so important. You can join us in helping raise awareness to others who might be going through this.

Here are some actions you can take:

- **Share your story through the Arthritis Foundation!** Your experience keeps us better informed to help us advocate together. The **Live Yes! Arthritis Network** brings us all together.
- **Consult your health plan materials and call your insurer to ask questions.** If you have been affected by this type of policy and have had to switch to another drug, or have been unable to fill your prescription, tell your insurer. They won't know unless you tell them.
- **Tell your employer, too.** They may not understand the negative impact it could mean for their employees and dependents. Contact your organization's human resources or benefits specialists.
- If you are unable to afford your prescription drugs, **patient assistance programs** may help. Visit the Arthritis Foundation's **Access to Care toolkit** for help navigating all aspects of health coverage.