Waste No Time

A tip on getting your insurer to pay for pricey drugs

January 1, 1999 By Sean Strub

Last spring, I started to waste, especially in my arms and legs. Usually when sitting, my thighs touch from groin to knee; at that point an inch-and-a-half gap had developed. My arms were skinnier than usual. My ill-fated two-week drug holiday in June greatly accelerated the process: I lost almost 20 pounds. To reverse the trend quickly, I began taking Juven, a multinutrient supplement. A friend, POZ contributing editor Stephen Gendin, recommended that I consider human growth hormone (Serostim, made by Serono); my doctor, Joe Sonnabend, wrote the prescription.

That's when things got difficult. My usual pharmacy couldn't fill the 'scrip because Oxford, my HMO, fills all Serostim orders directly from its own pharmacy. So Joe called them, but the rep put him on hold repeatedly, for up to 10 minutes. After four attempts over several days, Joe had to give up to attend to other patients.

So I called on speakerphone and waited while doing other work. Finally, a live voice answered. I conferenced in Joe to request the drug. Oxford said it had to be handled by their medical director (to whom neither Joe nor I had ever spoken), and Joe would have to fill out paperwork. He did so, the same day. A week later I was approved, and it took another week before I got the pills. Total time elapsed between prescription and drug? More than a month. If I'd had severe wasting, I might now be dead.

The managed care "system" is set up not to get PWAs the meds we need, but to discourage doctors from prescribing high-priced drugs like Serostim ($1,800 a week) and to make it as complicated as possible for patients—hoping we will give up or give out before the HMO has to cough up the drugs. It's a disgusting scam, but sadly commonplace for insurers, especially when patients seek coverage for new, less-proven or pricey medications.

The good news is that the Serostim injections worked, and fast. I had tremendous energy at the gym, working out longer and harder than I ever had in my life (and I'm no gym bunny), plus a big appetite and obvious gain in muscle mass within 10 days. I understand why bodybuilders covet this stuff. The Juven supplement had helped as well (and was vastly less expensive), but it didn't have Serostim's immediate effect.

Later, I found out that Serono's patient assistance program (800-714-2437) helps doctors navigate Oxford's maze. Obviously, the drug company is highly motivated to outwit each insurer's coverage-avoiding tricks. Apparently, some insurers will cover prescriptions for "wasting" but not for "lipodystrophy" (fat redistribution), even though many doctors use the terms interchangeably.

Most drug companies offer such patient assistance programs (some also provide free drugs to a limited number of uninsured people). For very expensive drugs, like Serostim, by not using such a program, you or your doctor may have no access to the product. Every question the insurer asks is designed to figure out how not to cover the drug.

Remember: Patient assistance programs aren't just for the uninsured. They're also for those of us with insurers that treat us like crap and could care less if we live or die.

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