Ouch!

For HIVers, the Vioxx saga is a tiny wince in a lifelong battle with pain. Here, what really works.

May 1, 2005 By Kristen Kresge

HIVers can be forgiven a collective snore at the media's newest medical obsession: the excruciatingly vague science of pain relief. Suddenly, pain afflicts the front cover of *Time, The New York Times'* science section and scores of TV news segments. It all began when Vioxx was bumped off the market last December. Along with Celebrex and Bextra—other Cox-2 inhibitors in the class of NSAIDs (non-steroidal anti-inflammatory drugs)—the blockbuster painkiller significantly raised heart-attack and stroke risk. Typically missing from the press frenzy was any mention of what Cal Cohen, MD, research director of Boston's Community Research Initiative of New England, calls the "additional burdens in diagnosing and treating pain" that HIV—and its treatments—place on patients and providers.

POZ took a look at how HIV pain experts shoulder those burdens, offering a short list of HIVers' most common hurts—and tips on top treatments. Plus, HIVers contribute remedies that aren't on Doc's formulary. "Many drugs are useful in treating HIV-associated pains even if they're not approved for that purpose," says Howard Rosner, MD, med head at LA's Cedars Sinai's Pain Center. (You may have to go way off-label—and mix and match remedies—to keep your pain from going off the chart.) As for the Cox-2 newsmakers, most HIV docs say they'll prescribe 'em for headaches and joint, muscle and back pain—but mostly for short-term use.

BIG PAIN #1:
Peripheral Neuropathy (PN)

WHY IT HURTS: PN's nerve damage numbs or inflicts a burning sensation on the hands and feet of about 30 percent of HIVers. Linked to "d"nukes—d4T (Zerit), ddI (Videx) and ddC (Hivid)—it can also result from HIV itself.

WHAT HELPS: David Simpson, MD, director of clinical neurophysiologyat Mt. Sinai in New York City, both studies and treats HIV-related PN.He usually starts HIVers on the least invasive treatment, such as Lidoderm, a lidocaine patch for post-herpetic neuralgia (a painful shingles after-effect; see "What Else Hurts," below). Second choice: antidepressants like the new Cymbalta or anticonvulsants like the new Lyrica (or the older Neurontin). If you're still hurting, Doc might try narcotics like percodan, vicodin or Tylenol with codeine. Studies show that drugs like the tricyclic antidepressant Elavil may soothe diabetic PN, which stems from impaired blood flow and high

blood sugar, but might not ease HIV PN, which has a different cause. Some HIVers swear by acupuncture; others try exercise, yoga, marijuana,hypnosis and anodyne infrared-light therapy. Ray, a 44-year-old New Yorker, says he got PN from Zerit. His doctor recommended B-12injections. “It took over a year, but that was the only thing that helped,” he says.

WHAT’S COMING: Simpson is planning studies of Cymbalta and Lyrica (both FDA-OK’d for diabetic PN) on HIV PN. He warns that the body uses the same route to process Cymbalta and HIV protease inhibitors, so doses might need adjustment when the two are paired. Trials of one pain-relief hope, Prosaptide, have been halted—at least for now—but high-dose capsaicin patches and carnitine are still in the running. (To find a carnitine study: www.clinicaltrials.gov, 312.572.4545.)

BIG PAIN #2:
Joint and Muscle Pain

WHY IT HURTS: Along with all the aches and pains all flesh is heir to, HIVers get to experience their own HIV-related ones, caused by certain infections, HIV arthritis, the meds or the virus itself. Two examples:Reactive arthritis (an after-effect of infection or injury) hits some50 percent of people with AIDS; osteonecrosis (bone death that causes joint pain) affects about 4 percent. Ariel Teitel, MD, a rheumatologist at St. Vincent’s Hospital in New York City, says osteonecrosis may link to long-term PI use. It’s also caused by steroids that treat PCP pneumonia.

WHAT HELPS: For joint and muscle pain, Teitel uses creams or patches like lidocaine. NSAIDs, Tylenol,acupuncture, massage and exercise are options. Tom, a New York city graphic artist positive since the early ’80s, suffers from HIV’s inflammatory joint pain. “Taken regularly, fish-oil supplements and anti-inflammatory herbs like turmeric reduce my pain,” he says.

BIG PAIN #3:
Headaches

WHY IT HURTS: Many HIV doctors say almost all HIV drugs can cause plain old headaches. Pesty infections like herpes can contribute; serious ones like CMV encephalitis and cryptococcal meningitis can create horrid headaches. But most HIVer headaches are garden variety, not related to the virus.

WHAT HELPS: No-brainers: aspirin, acetaminophen (Tylenol) or over-the-counter NSAIDs. But be sure to alert your doc to any new or severe headaches—especially with a fever.

The biggest headache to treating pain? It’s utterly subjective, varying from HIVer to HIver—as do remedies. “All treatments help a subset of people—one size rarely fits all,” says Keith Henry, MD, a top Minneapolis HIV doc. Remember that study showing that the supplement glucosamine, touted for joint pain, worked no better than a placebo? Don’t tell your friends whose knees it eased. LA’s Rosner urges relentlessly trying treatments—even in combination—until you find a winner. That’s what Gary, 55, positive since 1991, did. “I’d tried every med in the book for my PN. When I moved

to New York City from Cleveland, I turned to needles—a year of weekly acupuncture sessions finally got my feet to where I could stand, walk and live my life."

WHAT ELSE HURTS
Three more common HIV-related pain complaints:

NAME: Post-herpetic neuralgia (PHN) from shingles

WHY IT HURTS: PHN is a hangover of shingles—the blistering caused by herpes zostervirus—in which damaged nerve fibers continue to produce pain and burning.

WHAT HELPS: The topical Lidoderm patch is approved for PHN.
Some HIVers reach for low-dose capsaicin cream, the anticonvulsant Neurontin or tricyclic antidepressants like Elavil and Pamelor. Icing the area continually as soon as nerves start tingling can shorten PHN bouts.

NAME: Myopathy

WHY IT HURTS: Muscle inflammation leading to cramps, stiffness, spasms and weakness. It can be a toxic side effect of HIV meds like AZT.

WHAT HELPS: Switching the offending med may be necessary.
The amino acid carnitine may lessen the pain—and even repair muscle damage.

NAME: Psoriatic arthritis

WHY IT HURTS: Pain in the joints from inflammation caused by psoriasis, a skin rash common in people with faulty immune systems: Your immune system attacks your own skin; inflammation follows.

WHAT HELPS: Immunosuppressived rugs like cyclosporine, methotrexate, Vitamin A derivative, TNF inhibitors or Amevive are used to block the out-of-whack immune activity. UV light is used, too.
