

Todd Plumb, MD – “Dear Doctor” letter

Dear Doctor,

As you are probably aware, the fluoroquinolone class of antibiotics is useful for certain serious infections. Unfortunately, fluoroquinolones also have a long history of serious adverse drug reactions, many of them long term. (1) As a consequence of these reactions, several of these drugs have been removed from clinical practice or their use severely restricted. Besides the severe life threatening immediate reactions, those of a more chronic nature may occur.

The spectrum of these adverse reactions is extremely broad. Patients suffering from these reactions are often misdiagnosed, referred for a psychiatric consult or even unfairly labeled as "difficult patients."

Many physicians have not been properly educated about the severe nature of these chronic adverse reactions, some of which result in life-long disabilities. Post-marketing studies of several fluoroquinolones have shown an incidence of adverse reactions much higher than were originally reported in pre-clinical studies. (1,2,3)

You are probably aware that the fluoroquinolones are eukaryotic DNA gyrase and topoisomerase inhibitors very similar to many antineoplastic agents. Because of their similar mechanisms of action, it's no surprise that fluoroquinolones and many antineoplastic agents share similar toxicity profiles. Studies have even been conducted using fluoroquinolones to inhibit neoplastic chondrocyte growth in chondrosarcoma. (4)

There are many patients who have a syndrome of associated symptoms that include, but are not limited to: CNS agitation, depression, insomnia, new-onset anxiety and panic attacks, and even elevated intracranial pressure and visual abnormalities. They may also present with peripheral neuropathy usually of the small fiber type with temperature and pain sensory aberrations, but also often involving larger sensory and motor nerves. Spontaneous muscle activity with fasciculations, myokymia and myoclonic jerks may also occur. Many have musculoskeletal damage with degeneration of cartilage and tendons often leading to tendon rupture and severe ongoing musculoskeletal pain long after therapy has been discontinued. (1,2,3,4,5,6,7,8)

This complex symptomatology does not usually resolve after discontinuation of the inducing fluoroquinolone and may in fact worsen. Many patients go on to have disability that may persist for years. (1) Unfortunately, such patients are often seen by many physicians from multiple specialties who, given the complex symptomatology, fail to recognize a unifying diagnosis.

The mechanism of injury is not fully apparent, but several studies have been conducted and researchers have implicated the following possible mechanisms:

1. Inhibition or disruption of the CNS GABA receptor. (9)
2. Depletion of magnesium and disruption of cellular enzymatic function. (10)

3. Disruption of mitochondrial function and energy production. (11,12)

4. Oxidative injury and cellular death. (14)

This seems to be a functional disorder and structural abnormalities are not usually seen on radiological studies. (13) Patients may have abnormal EMG/NCV studies, abnormal skin punch neurologic density and morphology, abnormal vasomotor and sudomotor function on autonomic testing, and abnormal degeneration of tendons and cartilage on MRI. (13)

There may be a large number of these patients with coexisting endocrine abnormalities including: antithyroid antibodies and abnormal thyroid function, abnormal adrenal function with either hyper or hypocortisolism, hypogonadism, hypo or hyperglycemia and possibly impaired pituitary function. (13)

Most patients suffering from these side effects have a very clear onset of symptoms temporally related to a course of fluoroquinolone antibiotic. (13) They were often given the fluoroquinolone in conjunction with a corticosteroid or NSAID. Both of these classes of medications are associated with an increased incidence of adverse drug reaction from fluoroquinolones. (10,13)

As of yet no scientifically proven effective treatment is known, however patients will definitely benefit from your caring support and appropriate informed care. Of course, other diseases with similar symptoms need to be carefully ruled out.

There exists a large community of these patients who share information on the World Wide Web. Their numbers grow as the prescription of fluoroquinolones increases. Many of these patients are professionals like myself who have been affected by these drugs. Thank you for your time and consideration.

Todd R. Plumb MD

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Medical Professionals Who Have Been Affected by FQT

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- Todd Plumb MD on July 17th, 2008 <http://blog.pharmtech.com/2008/07/16/black-box-warnings-too-little-too-late-or-too-much/>

Fluoroquinolone antibiotics have damaged many people. I know of this severe damage on a personal level since I suffered such an adverse reaction to the fluoroquinolone antibiotic Levaquin myself 22 months ago. Since then I have had daily pain and disability of my nervous and musculoskeletal systems and for several months had endocrine and gastrointestinal problems as well. The disability and damage caused by fluoroquinolones is long term and may gradually escalate in that more severe problems such as worsened neuropathy, neuromuscular disorders, musculoskeletal disorders and endocrine disorders once initiated by the fluoroquinolones may develop with a delayed and insidious progress.

This progression of the fluoroquinolone toxicity syndrome is well known by its sufferers and not recognized by health care givers. There has been no investigation in to the reactions. This lack of attention stems from of an antiquated FDA reporting system and the inadequate under-representation of the seriousness and frequency of the adverse reactions. The makers of fluoroquinolones have no interest in investigating adverse reactions when doing so will hurt them financially. It is only recently with the weight of litigation pressing down that the FDA has published its incomplete and grossly inadequate boxed warning about the potential for fluoroquinolone toxicity. I have met many other patients suffering from the adverse effects of fluoroquinolones. Many of them reside in my community including 3 physicians and more than twenty patients.

Although these drugs may be life saving in certain infections when less toxic antibiotics may fail, they have been promoted for use as first line treatment for sinusitis, and urinary tract infections, and are often given indiscriminately to unsuspecting patients by uninformed and cavalier physicians for such benign illnesses as the common upper respiratory infection. Unfortunately for many patients they are trading a mild short term medical problem for a serious long term one.

Sincerely,

Todd Plumb

Dr. Todd Plumb

Many in the infectious disease community don't know about peripheral neuropathy with fluoroquinolones because infectious disease specialists rarely see the patient after the first consultation or hospital contact. These neuropathies peak after weeks to months and by then your fluoroquinolone prescribed patients are long forgotten. They go to their primary care doctor for help and he has no idea of the association. It is very clear that short courses can cause neuropathy from numerous patient reports. I myself suffer from severe neuropathy from a week long course of Levaquin. There is a very large community of patients (many who are physicians like myself) who have suffered from fluoroquinolone toxicity syndrome. The adverse event reporting system on its best days probably cover only 1% of these reactions. The toxicity of fluoroquinolones can be multi-systemic and not just limited to tendons and the peripheral nervous system, and it is much more common than you believe. The paucity of literature on the subject is because of publishing bias which you should be well aware of when trying to publish a report of a negative side effect or an inefficacy of a drug. It is because of social media that patients with fluoroquinolone side effects are becoming more recognized and has very little to do with the grossly inadequate FDA adverse event reporting system.

Dr. Edward Cooper's Avelox poisoning.

<http://www.levaquinadversesideeffect.com/2008/12/11/dr-edward-coopers-avelox-poisoning/>

December 11th, 2008

Edward's Story

I am a 54 y/o urgent care physician who was 8 months into rehabbing after ACL reconstructive knee surgery, progressing to the point that I was running regularly. I have recurrent sinus infections and had been advised by my ENT to have sinus surgery. I had been taking Augmentin for about a week but the infection was not improving. According to the Sanford Guide to Antimicrobial Therapy (the gold standard for physicians treating infections), for severe sinus infections lasting over 3 days without improvement, quinolones are the only meds listed for treatment. The Sanford guide was given to me by the Avelox representative, by the way.

On 5-28-04 I took one 400mg. tab of Avelox. The next A.M. I woke up with severe pain from my left hip through to my left foot. My left leg from the mid-calf to the entire foot was reddened and swollen with all tendons in severe, burning pain and all muscles were in painful spasm. I could only crawl to the restroom for my activity that day. There were also elements of depersonalization, anxiety and panic during this time. It is now eleven days since I took a single Avelox pill and I continue to have great difficulty walking with constant pain in my left leg, and increasing instability in my surgically reconstructed right knee along burning pain in both Achilles tendons.

It is all I can do to go to work and feed myself, finding it very difficult to tolerate much time standing and may have to cut back on my work schedule as I fear the rupture of my Achilles tendons or the AC ligament. I know from reading other postings that this process can take an indefinite period of time to resolve, if ever. I have never missed a day of work in almost 30 years of practice except for the knee surgery, but that may change soon if the pain, weakness, and instability of my joints continue to worsen.

The Avelox rep. did not even offer to report this as an adverse drug reaction and suggested that I was probably working out too much! I guarantee that I will actively pursue this progressive poisoning of our people with further research and political actions. They have been making "new, safe" quinolones for many years but the facts show that most of these are soon withdrawn from the market once they are taken by the general public and the adverse reactions occur. Is there any other product in the U.S.A. that can get away with stating that "if your tendons rupture, then stop taking our product"?

Story updated – 09/01/04:

This a 90 day update. There has been improvement my leg strength to the extent that I can use a recumbent bike and have progressed to an elliptical machine as of 8-04, but any attempt at prolonged walking leaves me with severe muscle spasm, Achilles tendon pain, and a rather alarming instability of my surgically reconstructed right knee. The right leg became symptomatic about a week after the ADR, with searing pain in the ligament and all tendons. Recently, I have had increasingly severe CNS symptoms with floaters in my eyes which are very dense and

almost curtain-like along with anxiety and insomnia which requires three 3 mg. melatonin at bedtime. I have developed severe photophobia which primarily occurs after exercise. I have a cyst on my kidney and on tendons of my left hip, these enlarge after activity. It's hard to believe that less than a year ago, I could do any level of step aerobics and could dance as well as most of the 20 somethings in the classes; an activity that I had been doing for about 12 years. I live a very withdrawn life now, the depersonalization symptoms became so bad, that at one point I actually had to sit down and make an outline of my life as I remembered it. Memories of the first two months of the ADR are of coming to the clinic where I work an hour early to put hot packs on my hips and legs and still feeling that my torso would actually fall down through between my legs if I continued to stand for periods of time, trying to do an upward facing dog yoga pose and feeling tendons pulling away from their bony attachments to my frontal pelvic area almost like tissue paper, or having to get my food at a drive-up restaurant because I could not stand long enough to make my own meals, then realizing that the ADR would relapse severely from eating meat, especially poultry. Of course these problems are really quite minor compared to the other stories on this site and are almost amusing to me now, until I think about the plans to get these poisons authorized for young children. I continue to only be able to work 3 days per week but I will continue to actively pursue my attempts to return to full function and campaign to have these drugs only available through infectious disease specialists and hospitals. Please, if you are an FQ victim, make reports to med watch on a periodic basis to indicate that these ADRs are not short term and can affect our lives severely for long periods of time.

Story updated – 07/30/05

I meant to provide a one year follow-up but am only now recording my experiences after over one year from the ADR.

I continue to have periodic episodes of tendinopathy with instability of ankles, knees, hips and even low back with ongoing pain and increasing weakness of lower extremities. My left Achilles and plantar fascia are becoming more loose with each cycle with increasing nodularity at the tendon attachment at the heel.

It's been 4 months since I have eaten away from home, the last time was when I could not stand it anymore and had BarBQ in Oakland and was unable to ambulate for 2 weeks due to pain in hips. I was unable to work for 6 months since last fall after being able to work 5-6 twelve hour shifts in urgent care as well as work out with wts, and aerobics on days off.

My ACL repair has been affected: one evening I felt intense pain in my posterior rt knee, which subsequently became unstable. An MRI revealed that the replacement ACL had become "thin, and functionally incompetent", my ortho could understand this and prescribed further PT which really did not prove to have any lasting improvement.

I finally realized that the replacement ACL is from a cadaver Achilles tendon and it was also ultimately affected by the ongoing allergic/inflammatory or whatever reaction.

If I take aspirin, corticosteroid nasal spray, or NSAID I am unable to sleep due to the subsequent stimulant reaction which can resemble a severe panic attack. Even taking a soy

protein powder supplement which was once a regular part of my diet will cause severe muscle and tendon pain and further looseness of Achilles tendon.

So I must be very careful about diet and discover cross-reactions as I go. At least, I did not use the Vioxx samples that were given to me. Finally, as an MD for almost 30 years, I have become completely disenchanted with medicine as I increasingly view the continued “takeover” of medical education by the pharm cos., having recently read about a dorm residency that will actually be funded by them.

Anonymous Physician: <http://levaquinhurtme.weebly.com/>

This site exists as a means to share my story about how Levaquin (Levofloxacin) harmed me and could harm many others.

Before delving into all of the dirty details, let me tell you a few things about myself. I am a 34 year-old female physician and, up until 11 months ago, I was extremely healthy, active and athletic. I was swimming 1500 to 2000 yards every day when I was 9 months pregnant including the day I went into labor. Eleven months after my Levaquin exposure, I am a completely different person.

My intention in creating this site is to warn patients as well as other physicians about the little known dangers of Levaquin and other fluoroquinolone antibiotics such as Avelox (moxifloxacin) and Cipro (Ciprofloxacin).

One week after delivering my baby boy, I developed a serious pneumonia and was readmitted to the hospital. Along with many other medications, I was given Levofloxacin 750 mg IV with a dose of steroid. A sputum culture to determine sensitivity to various antibiotics was not done and Levofloxacin was continued when I was discharged because of its broad coverage. I was never warned about any of the serious side effects that could occur.

While the drug was being given in the hospital, I had pain in all of the tendons in my hands and feet, to the point that it was difficult for me to walk normally or operate my breast pump.

I also noted paresthesias (pins and needles sensation) in my forearms and hands.

After a couple of days taking the Levaquin, I bent forward to reach for my son and felt something "pop" in my mid/upper back. I had excruciating pain that really prevented me from using my right arm for about 8 weeks. This was presumably a torn muscle attachment. I couldn't lift my arm, sit up, take a deep breath, etc without horrible pain.

Since my husband and I are both physicians, we had a vague understanding that Levaquin and the other fluoroquinolones can cause tendon damage or tendon rupture. What I did not realize though, is that these problems, along with many others, can persist for months or years after treatment or, in some cases, can even be PERMANENT!

Long Term Harm

I am now 11 months out from the Levaquin fiasco and I continue to have debilitating back pain. My initial tendon symptoms resolved about a month after stopping the Levaquin, but then returned with a vengeance about 7 months later. I am developing new tendon pains every few days, in various locations including my shoulders, elbows, hands, knees, ankles, and feet.

I found little relief from Tylenol, Advil, or Celebrex and eventually moved on to Tramadol. I am in so much pain when I wake up in the mornings that I have to take the Tramadol just to get out

of bed. Even with the medications, I am in constant pain and struggle every day to care for my beautiful baby. When I lift him, it feels like my joints are going to tear apart at the shoulders and elbows. The only time I can relieve my back pain is when I am flat on my back in the playroom. I cry almost every day out of pain and frustration that this drug has robbed me of my health and my chance to enjoy my son's infancy. And NO...I DON'T HAVE POSTPARTUM DEPRESSION. I have constant, horrible, pain.

In addition to the pain, I have profound memory loss. After basing my career on my ability to absorb and memorize massive amounts of complex information, I am extremely frustrated when I talk and have word-finding difficulties, can't remember names or places, and have difficulty describing something that I just read.

Less debilitating, but still new and abnormal, my body "jerks" as I try to fall asleep at night. This feels like muscle twitches, mainly in my trunk, but also in my extremities.

When I wake up during the night with my son, my eyes are so dry that it is hard for me to open them.

Overall, I feel like I am 100 years old.

To the average person, these symptoms probably seem like the rantings of a hypochondriac and are probably unrelated to the Levaquin. I felt that way too until I found all of the other patients like me online and they describe the exact same symptomatology commonly with the addition of excruciating neuropathic pain, permanent vision impairment, ringing ears, and several other devastating injuries.

Anonymous medical professional:

A few days after finishing five days of Cipro I was walking leisurely when I felt a pop in my Achilles tendon and had to limp home about a half mile . . . The next day I developed hot stabbing pain in my lower legs that came and went – felt like getting stabbed with a hundred hot needles. Within a couple more days, I felt a pop in my other Achilles and now had difficulty walking or standing with both legs being injured. The hot stabbing pains spread into both legs, followed by weakness in those muscles. Then the hot stabbing pains moved into my ankles – again followed by weakness . . . and then into my arms, wrists, shoulders and other body parts, always followed by weakness in those parts. My lower legs no longer felt like part of my body but felt like modeling clay with a strange texture that did not feel like ‘me’.

I managed to go to work 3 days a week, for about 3 weeks until my hands became so weak that I could not even make a fist. By this time I had already consulted some of the doctors at work (I was a medical professional myself) about appropriate blood tests to run to try to find out what was going wrong with my body. Most of the tests came back negative. I had no doubt that my problems were an adverse effect to Cipro - these issues have all been documented to be caused by quinolones and all the first hand stories of numerous unlucky patients online attested to that, too.

I went on leave from work from and continued to see various specialist who finally agreed that Cipro was indeed the cause of my symptoms which included neuromuscular weakness, neuropathy, tendon and joint pain, and other adverse reactions.

After a leave of two months I returned to work able to grip and use my hands again but the tendon issues and joint damage eventually became so great that I had to go on leave again. . . . I’m about 20 months out from taking Cipro and still unable to work with my hands, I lost my job and my ability to practice my profession. I have been a guitarist / musician most of my life and now cannot play my instruments like I used to, I can’t enjoy simple pleasures such as hiking, running, working out with weights, or even playing a game of Frisbee. Tendon ruptures due to damage by Quinolone antibiotics can occur many months after stopping the drugs as admitted by the manufacturers, and there are victims of Quinolone drugs on the internet discussion boards who have ruptured (multiple) tendons years after taking Quinolones. There are now two black box warnings on Quinolone antibiotics – the strongest warning the FDA can require yet many doctors give these drugs out with abandon and the industry encourages the use of these drugs even when safer, appropriate antibiotics are available.

That may be profitable for them but at great cost to those with long term and / or permanent serious adverse effects . . . and to society.

Anonymous physician:

I am writing because I have just had enough of the ignorance of the medical profession about these drugs. First let me say, I am a doc as a disclaimer. I am not office based so I have never written an outpatient rx for a quinolone. In the hospital, I can place on 2 hands the times I have had to use in a 9 year career: for patients with multiple allergies that had serious infection we had to treat and those who had bugs resistant to everything but a quinolone. I was trained by conservative ID docs in my training so consequently I never jumped on the quinolone train so to speak. However, I know very well meaning ED docs and IM docs who easily write for these meds both po and IV without a worry even after the black box warnings. That is a mistake.

I took Cipro (first time ever) in July of this year (500 twice day for 7 days) for a suspected bowel issue/infection. 2 weeks after I quit it I developed severe anxiety AND started with left sided pain in "my tendon insertion sites." I remember telling my husband, this feels like my insertions are all aching. It involved mostly the left shoulder/scapula, left pec insertion, 4th and 5th metatarsal head of foot and aching in the quad insertion on the left leg near the knee. I also developed muscle twitching and new onset hypertension, as well as intermittent hand swelling.

Fast forward through MRI of left shoulder that killed me for 2 months before I could get the MRI, by which time that had abated pretty much and now developed arthritis pain in both my hands and still with tendonitis like symptoms in the sole of the foot and groin and even where the tendons insert on the side of my fingers. I had an extensive blood workup for rheum everything from scleroderma to lupus to myositis, all negative. Had EMG and NCV studies all negative. NSAIDS do NOT help at all. My pain is worst in the early afternoon into the night. Now, the only thing that treats it is a low dose Lortab and a Flexeril occasionally. It also helps the insomnia though I do notice I have improved from the anxiety standpoint.

Anyway, I went to Cleveland Clinic recently and was seen by a neurologist there. He told me he thinks it is Cipro toxicity, repeated the EMG which was unrevealing. I then saw a rheumatologist there who disagreed and had no idea other than the usual tendon rupture/tendonitis that is what we are all aware of. She had no idea about the subset of otherwise healthy patients who develop the arthritis, myalgias and neuro like symptoms. In fact she looked at me like I had 3 heads and I am a medical doctor. So, one says it is, the other says she has no idea but still cannot tell me why I have pain near tendon insertions, arthritis in knees and hands and intermittent hand swelling of fingers that look like little sausages and why I need Lortab to treat pain.

So, to all you out there who thinks this does not happen to MD, RNs etc, think again. It does and we have no better advocates than you do. I realize just how naive and underreported and acknowledged this problem is. The good thing to know is that a lot of my colleagues who used a lot of Cipro and the like have changed their prescribing habits because of what has happened to me. I am 40 years old and feel like an 80 year old with stiff aching noisy joints. Rheumatologists and orthopedists need to get with the program and realize this syndrome so to speak goes beyond the black box subset of patients known to be extra sensitive to quinolones "the renal failure and steroid dependent 62 year old with tendon rupture..."

So, we as MDs have a lot to learn about this myriad of fluoroquinolone drug class effects and when we see it and no other explanation is plausible, we owe it to our patients as well as our colleagues to report these disabling symptoms as ADR to the FDA. Maybe if enough MDs do this, the word will get out and more patients will not be "blown off" as head cases...

Good Luck to you. I did one of my residencies at a well known university on the east coast, to remain nameless. If other MDs on this board can attest, we still get skeptical colleagues and quite frankly I think some don't believe it. All it takes is one good case report in the NEJM and then all of a sudden like a lot in medicine it will be the vogue to diagnose it.

Anonymous medical professional:

I don't understand where the Hippocratic oath went? The scientists and doctors that are developing and prescribing the quinolones aren't following the oath, obviously. How can someone of obvious intelligence (graduated medical or pharmaceutical school) ignore the real statistics? How can they continue to give out quinolones unnecessarily? Other antibiotics work just as well on numerous infections. Less dangerous MRSA for example is resistance to quinolones, the antibiotic of choice is Bactrim (Trimeth/Sulfa). Physicians need to look at their hospital's antibiograms and prescribe the least toxic and least expensive antibiotic that is effective. Please quit letting pharmaceutical kick backs and ego stroking by them keep you from doing what is best for your patients. The pharmaceutical companies are out to make money, doctors are supposed to be about healing, all this damage can stop with the pen strokes that physicians apply to their prescription pads. The medical community needs to take its intelligence and use it with some common sense and sense of decency and accountability for the patients they serve. Quit writing prescriptions for quinolones, using quinolones routinely in the surgery suite when there are other drugs that are just as effective. If other antibiotics are not working and it is a matter of life or death for the patient, maybe quinolones would be a last resort answer, but only in those instances. You wouldn't give Vancomycin routinely, it is only used as a last resort, quinolones are also toxic and should be treated as such. I am a part of this community and advocate diligently against the routine use of quinolones, I am accountable for my part in a patient's care and take it very seriously. I would never unnecessarily put anyone in harm's way and I haven't taken an oath not to do so. My conscience takes care of that. Even if I wasn't one of the multitude of sufferers that have had their lives changed forever due to the quinolones I could not in good conscience ignore the damage quinolones are doing. Because I am a part of the medical community I do my best to inform the medical staff at my facility of the dangers of quinolones, I recommend safe alternatives by referencing an antibiogram. It's not that difficult to step up and do what's right. Physicians please join me and make your pen strokes honor your oath.

Posted July 10, 2008 at 04:29 AM

Anonymous DVM

Another life here completely destroyed over five years ago within a few days of starting Cipro. I am a veterinarian who has prescribed a lot of drugs for my own patients throughout my career, including plenty of antibiotics. The only good news to my story is that in hindsight, I'm so relieved I used the FQ's only very rarely, not because I knew of these severe systemic adverse effects in people (I didn't), but because I had been trained these were to be the antibiotics of last resort and I took the resistance issue so seriously. I had no idea that these antibiotics had basically become a "first drug of choice" antibiotic in human medicine until they were offered to me and after my own reaction.

I was a healthy, athletic, self supportive, active person working in a moderately physically demanding profession. Vet med is a little different than human medicine, in that it's pretty "hands on" for the vet. It was often me lifting that 70 pound dog up on the X-ray table and holding him down trying to get a radiograph, wrestling with him on the floor trying to get a blood sample, and dodging flying teeth at 3 am when it was just me and the owner present when I worked overnight emergency alone in a rural clinic. As far as anyone knew, I had no pre-existing conditions within myself or even my family history to hint at what was to come. I had no allergies, was not infection prone (I've never had a sinus infection and only 2 UTI's 30 years apart before taking the FQ), no co-morbid conditions, not on any medication, never did any illegal drugs, worked out regularly, have always been thin, ate organic when I could afford it, and although not an extremist, was your basic average joe "health nut" and in great shape for a 50 year old person. The day before taking the antibiotic, I could have gotten on my bike and ridden 70 miles. Five days and a few pills of Cipro for my second simple UTI in my life ended all that.

Day 5 I was hit with a bizarre extreme fatigue that I've never felt before, it's not your typical "I'm tired" or "fatigue" type of thing. I've heard it described as if one's "battery is unplugged", and that's a good description. I could barely keep moving. Day 6 the clicking and popping starting in my knees when I tried to crouch or kneel in the exam room while working with the big dogs; I'd never in my life had any knee or joint problems, and between this and the fatigue I felt "like I was a 100 years old". Day 7 the tendon pain started in earnest – in every tendon in my body. This, too, is not like any pain I'd ever experienced in my life – it was not the joints, it was not inflammation, it was simply every tendon in my body started with excruciating pain made worse with the slightest use, movement, or pressure. We're talking tendons in my feet, toes, ankles, knees, hips, back and torso, shoulders, elbows, wrists, every finger, jaw, eyes, even the periodontal ligaments around each tooth seemed to hurt. I could no longer vaccinate, grip a pen or syringe, do surgery or hold a dog; I could no longer stand or walk; with great effort I tried to hobble about with my weight resting on the lateral edges of my feet, and not bend my knees, eating was painful and left my jaws and teeth hurting. During this time the "hot flashing" started – not simply typical hot flashes, but feeling like I was being hit by a truck from the side, almost knocked over completely, while breaking out into a complete sweat and feeling like I was going to pass out and collapse. I remember standing in the room talking with clients, trying to support myself against the bench so I wouldn't fall over, hoping they wouldn't notice I was sweating and facing some inner unknown alien foe, about to collapse – and feeling how the tendon pain was worse simply because I been supporting my weight with my arms. By Day 9 it was all over – I left work early for the first time ever in my career due to feeling ill, and sobbed all the way home. Within a few days, I was completely disabled and bedridden with severe, generalized tendinopathy, extreme muscle weakness and fatigue, muscle and tendon fasciculations and jerking, strange peripheral neuropathies in my arms, legs, head and face, extreme general fatigue, severe "brain fog", hallucinogenic dreaming, severe headaches and intracranial head pressure, severe ear pressure and pain, nausea, tinnitus, extreme hot flashes, dry mouth, dry, painful eyes and vision problems, heart palps, tachycardia, arrhythmias, panic and anxiety, and feeling generalized extreme weakness. I was completely bedridden for the first 2-3 months or so. I had to lay in bed with my arms and legs flat out

straight because of the tendon pain. I couldn't type or use the computer, because every tendon in my fingers, hands, wrists, and arms were affected and severely painful. I couldn't hold up a book to read, because the weight of the book was too much and I couldn't bend my arms, without increasing the tendon pain. The weight of the sheets on my toes caused severe pain in the tendons there. I couldn't tell if I was asleep or awake; I've never taken LSD before, but I imagine it to be something similar, as I had these incredible vivid hallucinations or dreams day and night. I had to be pushed in a wheelchair to attend doctor appointments. It was months before I got up and was able to start painfully hobbling around in the house.

Symptoms slowly improved to the point I was able to walk around the house and out to my mailbox by about Month 6 post, and many of the other symptoms had improved quite a bit too. But then in Month 7 post I discovered my glucose fluctuating between 50 – 250 mg/dl. Month 8 post I acutely developed new/renewed CNS, PNS, and ANS symptoms with a vengeance, along with all the food intolerances. I then continued to regularly suffer additional other acute massive attacks every 6-12 months over the next several years of whatever it is this toxicity sets off, leaving me once again bedridden for virtually all of 2013 and 2014. By the way, extensive testing via the traditional medical community comes up all negative or WNL. This includes no elevated inflammatory markers what so ever, even during the acute phase or "flare attacks". It's been over 5 years now, and my symptoms have remained 1) consistent over time, and 2) consistent with those of other sufferers of this condition, although in an overall fashion, I slowly but surely continue to decline, if for no other reason than it's terribly unhealthy to live such a limited life physically. Eventually, like many others, I discovered anti-thyroid antibodies, but that's been the only objective abnormality so far, other than severely dry eyes confirmed with STT=0 test. Astoundingly enough, on paper, for the most part, I am the picture of health.

In general, I haven't had a problem with physicians denying the FQ as being the causative agent in my symptoms. The only one who was skeptical was a University based research rheumatologist, of all people. I specifically chose him because he had written a paper on tendonitis, and had mentioned the FQ's as a cause of "tendonitis" in his research paper. However, when he saw me, he decided my sudden whole body tendon issues were "coincidental" in relationship to the FQ's! I guess he was more than willing to repeat what others had said about this rather unique and unintuitive, but well known adverse effect of FQ's in his paper, rather than risk diagnosing his very first case standing right in front of him.

The doctor who Rx'd the FQ, and who had "never seen a FQ toxicity before", did not deny it, as she watched the whole thing play out before her own eyes. Since then, she's a general practitioner who recognized it in several of her patients within the first several months post my own reaction; imagine if all doctors did this. I suspect the numbers of those of us affected would be increased quite a bit, ranging from milder cases of carpal tunnel and plantar fasciitis with "no known cause", to all those torn cruciates, menisci, and knee damage, to the panicky CNS "anxiety and stress" patients ending up in the ER, to the severely disabling and crippling cases of generalized tendinitis, peripheral neuropathies, and fatigue often diagnosed as one of the "mystery illnesses" (chronic fatigue syndrome, fibromyalgia, seronegative autoimmune diseases, etc.). I've also met several physicians who told me of cases they were aware of as well, including one physician who lost one of her own staff members to permanent disability due to Cipro.

Supposedly, these reactions are considered "rare". However, when my doctor left the practice, I was randomly assigned a new one. When I asked him if he had heard of "FQ Toxicity", he sadly nodded his head yes. He'd had a Levaquin case that had "never recovered". I then went for my annual wellness appointment. The NP seemed quite interested in hearing my Cipro story. When I told her, she said one of their staff had been hit and become completely disabled, living in pain in a wheelchair. That had been

over two years ago, and it didn't look like she was coming back to work anytime soon. I went to see an orthopedist. She told me she had done several surgeries to repair fluoroquinolone induced tendon ruptures. My neighbor approached me the other day, and asked: what was that antibiotic you took? A friend of hers had taken Cipro and three weeks later ruptured both Achilles. They could not be repaired surgically, and the doctors have told her she will never walk again. She's only three months out, but is now developing the additional delayed symptoms of "the syndrome". Worst of all, I warned the last practitioner I saw of these reactions. He said he'd heard of "the tendon issues", but not the systemic-like reactions. I told him that in my opinion this class of antibiotics should never be prescribed for people with pre-existing or even suspected endocrine problems, in particular thyroid problems. Maybe he forgot what I told him. Maybe he thought I was exaggerating or being alarmist. Maybe he thought I was making it up. But for whatever reason, it was not even a week later that he prescribed Cipro to a person on thyroid medication, and within 5 days she was down – completely disabled and in severe pain. Through complete coincidence, she somehow tracked me down. She was asking me what could she do? Her kids and family were depending on her. I didn't have the heart to tell her that her kids may have just lost the mother they knew, her husband may have just lost the wife he married, and she may have just lost whatever future life she wanted for herself. No matter how "rare" these reactions are supposed to be, that does not justify the loss of quality of life that occurs for those of us who have been affected.

I was never able to return to work. I lost my health and physical abilities. I lost my professional career. I lost my 30 year partner and marriage. I lost my financial solvency. I lost friends and acquaintances, as they moved on with their busy and active lives, while mine stopped completely. I lost any quality of life and my future, and I am slowly but surely losing hope of ever truly recovering. The suffering is indescribable, incredible, and inescapable. And the key word here is SUFFERING, in capital letters. This "syndrome" of adverse affects is a full body and mind experience, with no relief in sight.

It's one thing to take a "benign antibiotic" for a simple uncomplicated infection and maybe experience mild transient side effects which stop and go away once the antibiotic is stopped. It's another thing entirely to take a "benign antibiotic" for a simple uncomplicated infection and become permanently disabled for a lifetime, sometimes as a result of taking just one pill. If the odds of experiencing a mild transient adverse effect are 1/100, I'd bet most people, myself included, would be willing to risk that in order to clear up a simple UTI. If those same odds may result in a lifetime of severe pain and suffering as a chronic disabled invalid, I think most people, myself included, would think the risks are too great to use that drug for a simple UTI. I had no idea I'd be in that one percent or less, and now that I've found out, it's too late.

Like other medical professionals here can attest, the shameful thing is that we only learn about these reactions through personal experience after the fact, or the experience of others such as on the internet. At this point in time, I'd believe these stories before I'd believe anything the pharmaceutical companies, the FDA, and the medical profession has to say about these drugs. Don't hold your breath waiting for the FDA or Big Pharma to adequately and appropriately warn you, or for "unbiased" case studies funded via Pharma proving the "relative safety" of this class of drugs. I wish so much that I had read the internet BEFORE taking the drug, and hope to god I would have believed what I was reading. As I can now attest, these stories are unfortunately very true. I regret every single day for the past five years that I ever even considered a fluoroquinolone antibiotic for my simple UTI. I paid for my own ignorance with my life.

Anonymous physician:

CIPRO

Yes, the Fluoroquinolones can cause a severe reaction that hasn't been fully appreciated by the medical community. I am a physician and I know how ignorant we are with regards to the side effects. The FDA warning doesn't take a strong stand against the side effects and fails to mention that Fluoroquinolones lead to a SYNDROME with many side effects. To believe this class of medications causes one or another side effect is completely irresponsible of the FDA. As a physician and as someone that is suffering the Fluoroquinolone syndrome/toxicity, I beg the FDA to limit the use of Fluoroquinolones to life and death situations, and to recognize that Fluoroquinolones can lead to a syndrome that can last months if not years. If it wasn't for my vacation and sick leave days, and the kindness and understanding of my employer, I would be out of a job! Yes, a Physician at age 43 out of a job and on disability.

This is preposterous to say the least. The FDA must take the sufferers seriously. I have reviewed many scientific articles and they are all fixated to within the author(s) specialty. Fluoroquinolones affect many organs and need a generalized scrutiny. I was well aware of the possibility of the tendinopathy from Fluoroquinolones, but I wasn't aware of the syndrome that ensues.

Prior to this toxicity, I was a healthy, physically active person. I had NO medical history. For God's sake, I had never taken any meds except a few Motrins and Tylenols here and there. This medication has completely made my life miserable. I feel like a 300 year person. Please, I beg the FDA to take a moral and ethical stand above monetary gains, and limit the use of these meds, and to better inform the public of the syndrome that may arise, and believe me, as a sufferer, the symptoms aren't your garden variety symptoms. THEY ARE FROM HELL!

Anonymous physician:

Aug. 23, 2012

First off, I am a physician and I want everyone to know that the medical community has no idea how dangerous fluoroquinolones are! There are bits and pieces of its dangerous side effects in the warnings, but there is absolutely nothing on how dangerous, intense, prolonged the side effects can be. Fluoroquinolone side effects manifest as a syndrome that is unknown to the medical community. That is why when you have multiple and evolving side effects, your doctor denies your symptoms being caused by taking fluoroquinolone like Cipro. The side effects of fluoroquinolones can manifest months after you ingested the last pill and the ignorant medical community will miss linking your misery to the fluoroquinolone poisons, since it is very difficult for them to believe that a pill you took 9-12 months ago can cause side effects this far out.

I was one of those ignorant doctors! I didn't learn any of this in medical school, residency or my years of practice. I trusted the FDA and their scrutiny of these drugs, and nowhere in the warnings does it indicate a fluoroquinolone syndrome. I have yet to see a single medical article on this syndrome that hundreds, if not thousands of people are experiencing. Unfortunately, I got a taste of my own medicine 7 months ago when I took Cipro for a few days for a Dysuria. At first, I noticed loss of sleep. The next day, I developed severe bilateral ankle pains, unable to walk, and from there have had 30-50 side effects that have evolved and cycled over the course of several months.

Some symptoms were night sweats, difficulty swallowing, arthritic joint pains, severe fatigue, myalgias, severe anxiety and depression causing suicidal thoughts, severe burning in the arms and legs, and the list goes on and on. I am 7 months out since the last pill and I am still suffering, though I have noticed some improvement in my symptoms. Should fluoroquinolones be avoided? Absolutely, unless there is no alternative, which means limited to ICU setting.

I am a powerless person. If anyone out there has any clout over the FDA or any government agency, please do something to limit the use of these poisons in the outpatient setting! I was a healthy, athletic person without any past medical history and now I have between 30-50 illnesses, basically every organ in my body has been affected. I am ashamed to say this, but the best source of knowledge have been the sufferers, since the medical community has zero to offer and in fact, out of ignorance may harm you. In my experience, speaking to 10's of sufferers, including other doctors that have suffered, you will get better in time. Meanwhile, you will suffer for months and possibly a few years.

ENT Physician: Lawrence W. Rodgers, Jr. MD

Dear Colleague:

I am writing this letter to describe my journey as a physician in understanding the potential devastating and life altering side effects of Fluoroquinolones on patients. I am a practicing ENT physician in Florida. My training included Medical School at the University of Florida where I was Alpha Omega Alpha and graduated 10th in my class. Residency training as an Ear, Nose, Throat and Head and Neck surgeon was completed at the University of Florida.

During my career as a physician in private practice I have prescribed oral Levaquin, Avelox and Cipro for over 20 years. Usually this was given for chronic sinusitis.

My wife was given oral Levaquin twice, Avelox once and then Factive over a four year period of time. Her first Levaquin precipitated peripheral neuropathy in August 2008. She had persistent and then worsening symptoms since that first injury seven years ago. In retrospect she suffered acute onset connective tissue symptomatology, severe neurocognitive injury, marked prolonged fatigue and peripheral neuropathy related to taking these antibiotics. The onset of these side effects varied from acute, within a few days of beginning the drug to later onset. To this day she suffers ongoing peripheral neuropathy, neurocognitive difficulty and persistent fatigue with joint and back pain, also visual change and thyroid dysfunction. Her life has been permanently altered. I consider myself a good physician but I was unable to recognize these injuries as arising from the Fluoroquinolones because I was not looking for these drugs as the culprit. The differential diagnosis was complicated. Now I realize these medications as the direct cause and effect.

As I realized the potential side effects of Fluoroquinolones I began looking for this in my patients. In my experience over the last two to three years three patients come to mind. One who experienced acute significant vertigo lasting almost three months from the use of oral Levaquin. A second patient with acute onset severe debilitating lower extremity pain from oral Levaquin caused him to be unable to work as a truck driver for two months. A third patient is a 23 year old girl given oral Levaquin by her primary care physician for sinusitis. She immediately experienced severe ankle and foot pain within a few days of taking oral Levaquin. This patient worked as a horse trainer and rode horses daily. She quickly became unable to do her job because of severe ankle pain as she tried to place her feet in the stirrups as she rode. The patient was referred to me because of persistent sinusitis. This was cleared with the use of other antibiotics. My young patient had persistent ongoing debilitating ankle and lower extremity pain and was unable to continue in the work she enjoyed. This was noted at her last visit with me to be persistent six months after discontinuing the Levaquin. More details concerning these patients are available if you would like to discuss them with me.

This is anecdotal but caused me to review other information and studies of the potential side effects of Fluoroquinolones. In my experience I conclude these are dangerous and potentially life altering medications and should only be used in life threatening situations. The most important adage I learned as a young medical student was "First do no harm", a very valuable basic principle for any physician. It is

my belief and experience that the over prescribing of these antibiotics violates this basic principle of medicine. I no longer prescribe Fluoroquinolones to my patients. I will be happy to discuss my experience at any time.

Sincerely,

Lawrence W. Rodgers, Jr. MD

Otolaryngology

Physician

Dr. TB (English not first language)

Sep 17, 2013

Dear Dr. Paul, there is no need to take fluoroquinolones for long time have to neuropathy, it is enough to take one tablet to have irreversible one, that is happened with me personally after taking Levofloxacin one and half years ago, in spite of using them several times previously as short courses, I am still suffering mainly of sensory neuropathy which did not respond to any treatment you know of including steroids pyridoxine ,B12, vit.E, and many empirical therapies ,it looks like an idiosyncrasy reaction which can happen anytime, it is rare but a very painful experience to such a side effect.

Physician

Dr. EW

I completely agree with Dr. B's comments. I was given Tequin in 03 for a respiratory infection- a standard 10 day prescription but didn't make it past day 4. Tequin all but killed me and I mean that literally. I ended up in the ER . I had been in out of consciousness for several days similar to how heroin addicts nod (severe dysglycemia). My husband rushed me to an after-hours clinic and they immediately sent me to the ER. After the ER visit I came home but I was in excruciating pain for months to the point that I had to sleep on the floor in order to create the least amount of resistance for my muscles. Trying to get out of a bed or off of a sofa would just about send me through the roof with pain. I felt as though I had glass shards pulsing through my veins all the time, my Dr. told me that my sed rate test was indicative of someone with severe Lupus (which she wanted to suggest I had..WRONG) I was bruising horribly and to this day have severe varicose veins and swelling. I also had other issues with hearing and eyesight. I had horrible tinnitus that took about 2 years to resolve and my ' perfect' eyesight was lost forever and I've had to wear prescription glasses for both reading and distance ever since.

Another poster mentioned that doctors are not acknowledging side effects. That poster is correct. Thank goodness I had enough insight and intuition to know that the drug was harming me and to do the research. But a patient in my condition should never have to do that.

Physician

I D

12 days ago

I have used fluoroquinolones on many of my patients and indeed the neuropathy from Ciprofloxacin can be so severe in prolonged use requiring immediate stoppage of the anti-

biotics. When the anti-biotics are stopped early enough, recovery with the use of strong multi-vitamin/multi-mineral capsules such as Peditvit Forte and occasional inclusion of the usual adult Amitriptylline dose for pain can take as long as 8 to 12 weeks.

It is good to warn the recovered patient never to take the fluoroquinolone anti-biotics again, because the neuropathy will recur with more intensity and can be irreversible.

Difficult patients are those on second line anti-TB fluoroquinolones such as ofloxacin and levofloxacin.

Physician Assistant

Have had one patient return 2 weeks later for a routine GYN appointment after a quick 3 day Rx for Cipro to treat a UTI. I inquired about her crutches, she informed me her Achilles' tendon rupture was attributed to the Cipro by her orthopedic MD. Thankfully no lawsuit was filed but since then I very strictly limit prescribing it!

Veterinarian

Dear medical community and other people posting:

I took Levaquin for 20 days for unrelenting pneumonia and at day 15 I began to have severe pain in my joints and tendons, this was in 2007. I finished the course as prescribed and went about my daily activities of running and yoga. I did not realize I had a tendinopathy due to the Levaquin and continued to injure myself. No one in the medical community would acknowledge this issue. I have seen several Docs over the past years all my tests are normal including family Doc, internal med Doc, Neuro Doc.

THANK YOU finally for this article! I think as many others that is very common. I have mild random shooting nerve pain mostly in my hands and arms for the past 4 years and I know now that I injure easily so I avoid injury and take this very seriously. I do not take any meds at this time for anything! My life has changed dramatically as well. I think I am lucky not to have suffered as much as others and if I had not had the pain and injuries, I would have thought the other folks in the chat rooms crazy. They are not, the side effects are common and real and I truly hope that the Docs out there will be more careful with this drug.

I can see over the past 6-7 years that each day in a millimeter kind of fashion I am getting better. I think there is hope for bodies to cure themselves with good nutrition, lots of sleep, kindness for one's self and time. For all of you that have suffered, I wish you well. For all the Docs out there, it can happen to anyone.

Thank you, RO, DVM (veterinarian)

Physician

Dr. S V

I was healthy and active until two years ago when I had to take Ciprofloxacin for a P.aeruginosa ear infection. The 5th day of therapy, I suddenly experienced severe acute pains in legs with tingling and numbness and disability to walk. Although I stopped the medicine immediately, my walking ever after was quite difficult, slow and painful. Three months later, I also experienced severe pain and disability in hands and arms. It is obvious that my life changed. Doctors thought that it was tendonitis as this is the only serious side effect of kinolones known in physicians. The connection of my symptoms with Ciprofloxacin seemed strange and difficult to believe. I was advised to do physiotherapies with low results. Finally, and although the HMG was normal, the Neurologist concluded that my symptoms accorded with peripheral neuropathy. After the first year of serious disability, I thought, I should try some alternative medicine since conventional medicine was unable to give me my health back. I feel quite angry that so many persons except of me have seriously suffered from a broad using antibiotic, while physicians have been and are still quite unaware. I can assure you that if I was informed of these serious side effects of kinolones, I would choose alternative ways to treat my infection.

Medical Doctor from Greece

Pre-Medical Student

I am a 23 year old student who took just 3 doses of cipro. The reaction started 2 hours after the first dose and over a 5 month period I've experienced over 35 symptoms. I was going to medical school this year, however now I have to put this on hold until late 2009 so that I can regain my physical and mental abilities to deal with university. I was very healthy prior to taking cipro, I never had any health major problems. Immediately after taking the first dose I got tingling, insomnia, tendinitis, nightmares and much more.

Eye Doctor

I have also been damaged by this antibiotic given to me for a simple UTI, prescribed inappropriately for 2 weeks! Thank goodness I stopped after 9 pills of cipro. Missed work for 2.5 months as an eye doctor, because I couldn't walk. I have ongoing pain and of functioning and it is now 4 months later. I have experienced peripheral neuropathy, tendon damage, crystaluria loss, gallstones, kidney stones, heart palpitations, intracranial pressure, blurry vision, vasculitis, etc. I have 3 small children and it has ruined my life. I forgot to mention the ongoing food allergies that have come up, can't have about 10 different things now, makes life very difficult. We have no one to help us get better or receive any compensation.

ICU Nurse

I am a 35 year old mom of three. An ICU nurse, cardiac and neuro (the irony!)

On June 2, 2011 I went to a 60 min spin class and lifted weights for a hour (typical Wednesday). I came home, ate lunch, and took dose #2 of Avelox. I left my kids at home with the babysitter and left for a meeting. On my way to the meeting (about 40 min after taking Avelox) my entire body went limp. It was heavy, could barely move my arms, legs, like someone was sitting on me. It was hard to breathe. Not fast, but hard. I had to concentrate and make myself breathe. I was lightheaded, tachycardic, and it felt like someone was pushing my eyebrows downward, it was hard to keep my eyes open. Everything was numb and tingling. I called my husband freaking out. I was sure I was having a stroke. He stayed on the phone with me as I drove myself to the ER, which was about 10 min away. As I got out of the car, my knees were buckling under me. I seriously thought about crawling. I couldn't hold a pen to sign my own name.

Long story short, I had every test known and unknown to mankind done. I was in the hospital for a week, being in the PCU for three days. Everything was "normal", except my EMG. That was the most horrific thing ever. They tested my right side, and with every shock my entire body jerked. I felt like I had stuck my finger in my mouth and stuck it in a light socket. My doctors had no clue. Even after I gave them a 20 page report my husband got from Bayer stating all the possible ADRs. They didn't believe a atb could do this to me, and after 2 doses. They kept saying it would go away once I cleared all of it. Well.....we all know that isn't true.

I am now almost 6 months out. I have peripheral neuropathy, I would say moderate to severe. It was pretty bad burning, numbness, tingling, pins and needles. But I started on a couple meds a few weeks ago - recc to me by a friend who is a radiation onc, he gives this to his pt's that have neuropathy from chemo- and I'd say its prob 90% better, tolerable. I have fasciculations (not visible) in my legs and arms. I feel like I'm shaking and revved up all the time. Therefore, if someone lightly touches me I jerk.

Ahhh, the myoclonus. My enemy. I will come back to him. I have the tendonitis, it comes and goes. I feel like I have the flu most of the time, although that is getting better. It cycles. I have autonomic neuropathy. I get really hot, then really cold. Palpable to others. I can't regulate my body temp at all. Random tachycardia. Not just fast, but hard and fast. Daily headaches, migraines. Panic attacks. They are horrible. I have one every time I try to take medicine. My personality is different. I'm kinda grumpy, and can't tolerate a lot of stress. I'm back to working out. I'm about 75% at where I was before. I try to work out hard, but it's like I hit a ceiling and can't bust through. It's very weird. I've always been athletic and workout 5-6xs a week.

The myoclonus. I've had it since the hospital. I would randomly jerk. A lot. After the EMG it was bad. With any type of test I jerk, a lot. Even just a pin prick test for my numbness. It's like my whole body gets revved up, and with any stimulation I jerk. Esp light stimulation.

Pharmacist

I feel that it is only a matter of time that the correlation is made between these side effects and the drug. Dr's are truly ignorant of the association between fluoroquinolones and the severe effects that they have on a small percentage of patients. I'm a pharmacist. I truly thought that you only have to watch out for the Achilles and rotator cuff tendonitis LIKE THE PACKAGE INSERT SAYS in the black box warning. WRONG! I'm two years out from this garbage and I have ankle, toe, foot, knee, thumb, wrist, elbow and shoulder problems. The popping and grinding is the most frightening. The drug company must know but they have too much invested and are making too much money. I work at a hospital and we do a ton of Levaquin. It's not cheap. I would bet the drug company knows that it is hard to definitively make the connection between delayed side effects that can be caused by other things (tendonitis from overuse etc). I think this class should be reserved for truly life threatening illness.

Nurse

EXCRUCIATING PAIN TO JOINTS!!!! I cannot bend my knees, can't even get up from sitting position. After trying desperately to figure out why my right wrist and fingers were hurting so much, I blamed it on my job (an RN), but when the pain started to spread throughout my other joints (knees, opposite wrist, toes -yes, even those) I went online suspecting this drug and BINGO, I read all the comments here and made the connection, it is this drug, as I realize all the symptoms started right after my second pill, and have gotten worse to the point that I cannot bear weight on my extremities, support my body on my hands to even get out of bed, and writing is just horrible. I'm only 32 years old, feel like 90. The sad part is, joint pain is only slightly mentioned on the medication side effects.

Nurse

I am a Registered Nurse of 37 years. I was given Cipro ear drops for a bleeding ear, to find out it was perforated. My legs became weak and inflamed. I COULD NOT WALK THE HALLS TO DO MY JOB AND WAS TOLD I COULD NOT USE A CANE. That same hospital forced me to leave after 2 separate prescriptions of Cipro affected my vision and made me suffer severe dizziness. I fell in the parking lot and down the hospital wet steps. I was forced out of my position as a Case Manager. I went to bed for over a year, sometimes crawling to the kitchen. I finally went back to Henry Ford Hospital in Detroit. It took me 11 months, and 12 Doctors, and \$16,000 to be insulted, mistreated, dismissed and told it was all a psychiatric conversion disorder. THE MORE ARTICLES I HANDED THE DOCTORS ABOUT FQ TOXICITY CAUSING NEUROTOXICITY, CFS AND MYALGIC ENCEPHALITIS, THE MORE THEY WROTE UNKIND THINGS ABOUT ME. I cannot drive, or walk greater than 30 feet, or shop, or cook, clean or participate in any life skill. I lay on the couch, depleting my life savings. I was treated with prejudice, disdain and contempt. I enrolled in the UC -Davis Study. I am heartbroken that those highly educated Doctors refused to even consider a health professional with 3 degrees and 37 years just wanted attention. My bank account is bleeding and I have decided to never go to see another Doctor again. This is a National Crime that a chemotherapy drug was amped up with a Fluorine molecule to treat Anthrax and Plague, and had 2 black box warnings. I just turned age 60, cannot retire, and not one Doctor would write in my record that it was a possibility that Cipro caused my tendonitis, neuropathy, blindness, tinnitus, vertigo, weakness, fatigue and severe myalgia and global body pains. I HAVE ENVELOPES ADDRESSED TO EACH ONE OF THOSE 12 DOCTORS FOR MY DAUGHTER TO MAIL MY OBITUARY TO THEM WITH A THANK YOU CARD WITH A PICTURE OF ME TO MY FORMER COLLEAGUES WHEN I FINALLY BECOME BRAVE ENOUGH TO END THIS HELLISH EXISTENCE. No one should be dismissed and ignored this way.

Physician: Dr. Keith Jeffords, MD

Dr. Keith Jeffords, from WSB-TV News Story, Feb 2015: Patients suffer devastating side effects from popular antibiotic

<http://www.wsbtv.com/news/news/local/patients-suffer-devastating-side-effects-popular-a/nj4Br/>

“It was an amazing amount of pain, to the point that I literally couldn’t walk. Plastic surgeon Keith Jeffords emailed [the news station] too. He received the brand name Levaquin after ulcer surgery. When his doctor refused to switch the drug, Jeffords fled the hospital. “They took me down to the base of the hospital in a wheelchair and I crawled on all fours out to my car and drove home”. Jeffords says he never got the warning either. “I’ll tell you, as someone who has been through Levaquin, you know, I will not prescribe that drug in my office.” Jeffords says his legs were weak for months.

Physician

After a medical degree, and lots of knowledge, I have to admit: I have parts of my body that hurt and I didn't know they existed. No bartending shift, no gym day, no golf/softball/football/soccer/cross country day ever made me hurt this much. Yes, I'm 40 and things go south, but screw Levaquin and its flox side effects. I'm 40, not 80.

Nurse

Thank you for airing this story! I was a RN for over 18 years & was very active & had a zest for life. In Oct 2013, I took Levofloxacin for sinusitis. After only 5 days, I became so ill I could only lie in bed & could barely walk. I have been disabled since. I have brain & nervous system damage. I have no energy, pain every day, tendon issues, I have balance problems, dizziness, & much more! I was never even aware fluoroquinolones could be so dangerous. I am thankful that others are coming forth to talk about their experiences & to raise public awareness.

Physician's Wife

My husband is a physician and he stopped RXing it a year ago. He will never prescribe this drug again. He said that physicians hand it out like candy and it should probably be prescribed about 1% of the time. There are alternatives. This newscast has enlightened us in many ways.

MedScape Article With Discussion Comments From Medical Professionals (11/6/2015)

Google the title “**FDA Panel Says Fluoroquinolones Need Stronger Warnings**”, by Troy Brown, RN. By doing a search on this title, you can skip the sign-in wall and get straight to the article and comments/discussion. Comments are only open to physicians and other medical professionals. There are approximately 174 comments in the discussion section.

Jay S. Cohen, MD

Fluoroquinolone Toxicity Syndrome: A Letter to the Senate Committee on Health, Education & Labor

May 9, 2014

To: The United States Senate Committee on Health, Education, Labor and Pensions

Re: Fluoroquinolone Toxicity Syndrome (FTS)

Dear Senators:

Serious adverse reactions to fluoroquinolone antibiotics (FQs) have been reported in medical journals and to the FDA since the 1980s. Although the FDA has increased the warnings on these drugs (Levaquin, Cipro, Avelox, Floxin, Norfolk, Factive), my analysis of FDA data shows that reports continue to climb in number. As of February 2014, approximately 45,000 individual cases of fluoroquinolone toxicity have been reported to the FDA. And, as studies have proven, the FDA receives reports of only 1%-5% of the actual numbers of adverse reactions that occur.

I have been following these medications for 16 years and have evaluated in person or by telephone consultation more than 400 people injured by FQs. In 2001, I published an article, Peripheral Neuropathy with Fluoroquinolone Antibiotics, in the Annals of Pharmacotherapy. This article described 45 cases of severe neurological symptoms such as tingling, numbness, burning pain, twitching, and/or severe weakness. Moreover, 93% of the subjects sustained injuries to other vital systems: agitation, impaired cognitive function, intractable insomnia, hallucinations, psychosis, acute manic episode, joint or muscle pain, or tendon rupture. In many cases, toxicities also involved the cardiovascular and gastrointestinal systems, skin, and sight or hearing. Overall, the majority of my subjects experienced toxicity to multiple body systems. Hence my coining the term Fluoroquinolone Toxicity Syndrome.

Of greatest concern, the majority of my cases had lasted more than 1-2 years and were ongoing. These severe, long term reactions occurred in a generally young and healthy population. The average patient age was 42, many of them athletes. In fact, top athletic organizations now warn athletes to avoid treatment with FQs.

Because of the impaired healing seen in severe FTS patients, we have long suspected genetic injury from FQs. These drugs were designed to injure the genetic structure of bacteria and thereby kill them, and they are very efficient in doing so. However, testing was never performed to ensure that FQs did not also injure human DNA. A recent study using high performance liquid chromatography with mass spectrometry has demonstrated that FQs do indeed injure human DNA. Further study on this must now be undertaken.

There is no doubt that fluoroquinolones are important medications that help many thousands of people each year, but the indiscriminate prescribing of these highly potent, "big gun" antibiotics for everyday minor infections such as sinusitis, sore throats, or bladder infections is unnecessary and medically negligent. Medical authorities have repeatedly denounced the overuse of FQs. In my 40+ years in pharmacovigilance, FQs surpass Vioxx and thalidomide in the degree of permanent harm done.

FDA warnings currently describe many of the adverse effects of FQs. Recently the FDA has finally acknowledged that FQs can cause permanent injury. However, FDA warnings do not adequately describe the FTS syndrome, so doctors do not consider FTS and instead waste valuable time and expense testing for rare neurologic or rheumatologic disorders, meanwhile discounting or dismissing patients who are suffering severely from FTS. The warnings must be improved and the word about FTS must be spread

nationally and worldwide. It can start with you. If you still doubt what I have written here, please examine the extensive literature on FQs toxicity beginning with the articles cited below.

Jay S. Cohen M.D. has been a faculty member at the University of California, San Diego, for three decades and has published more than 20 articles on drug safety in leading medical journals. Based on his articles and books, the FDA chose him as the keynote speaker at a FDA conference in 2004. He has debated FDA officials on drug safety strategies at conferences for the American Society for Clinical Pharmacology and Therapeutics and at the Drug Industry Association. His work has been highlighted in major newspapers and magazines including the New York Times, Newsweek and others. During the anthrax scare of 2001, Dr. Cohen's article on FQs and his appearance on National Public Radio led the CDC to withdraw its recommendation for Cipro for treating anthrax exposure in favor of other, safer antibiotics.

Important Articles on FTS:

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