AiArthritis Alerted to Rheumatology Patients Being Forced to Sacrifice Their Treatments Due to COVID-19

Autoimmune and Autoinflammatory Diseases that include inflammatory arthritis as a significant clinical component (AiArthritis Diseases) are full-body conditions affecting joints, tissues, and organs. Given these diseases are heterogeneous (unique per individual), finding the right treatment can take months or years.

Most patients with these chronic conditions are prescribed disease-modifying antirheumatic drugs (DMARDs), including biologics, to manage their disease, but there's no one-size-fits-all therapy, and responses vary per individual. The right therapy can be life-changing; disrupting continuity of care is strongly discouraged, as it can result in compromised quality of life, loss of employment, and comorbidities (such as heart, eye, and small vessel issues, or multiple disease diagnoses). But to accommodate hospital inventory needs due to high COVID hospitalization rates, mostly attributed to those not vaccinated, chronically ill rheumatology patients worldwide are being forced off their treatments...and they are angry.

Erin (USA), diagnosed age 14 with juvenile Psoriatic Arthritis, says, “Throughout the pandemic the public was asked to protect the at-risk population by washing their hands, socially distancing, wearing a mask, and getting vaccinated. Now the ‘at-risk’ people must protect some who didn’t do their part?”

**Bottom line: This situation was, and still can be, preventable. If more people choose vaccination, hospitalization rates would decrease, and rheumatology patients may not be forced to sacrifice the treatments that work best for them.**

Tocilizumab (Actemra) IV (infusion form) – developed for inflammatory rheumatic diseases – is being used to treat critically ill, hospitalized COVID patients. Other drugs may be available soon, but current options are limited. Meanwhile, rheumatology patients are experiencing unnecessary high anxiety, fear, and uncertainty.

“Often patients on tocilizumab have already failed several medications, so we are careful to determine who can safely switch. Ideally, supply would match demand and we wouldn’t need to switch away from administration route (in this case tocilizumab infusion to injection) or mechanism (what the drug targets in the body),” explains Dr. Christie Bartels, Rheumatologist and Division Head of the University of Wisconsin School of Medicine and Public Health.

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2. [https://www.cdc.gov/mmwr/volumes/70/wr/mm7043e1.htm](https://www.cdc.gov/mmwr/volumes/70/wr/mm7043e1.htm)
The American College of Rheumatology recommends switching to tocilizumab injections when able, but some patients have tried and failed that route. Others are physically challenged from disease deterioration and unable to self-inject. Additionally, this recommendation may be short lived, as many patients have already been notified the injection forms are now being pulled, too.

The shortage begins

For months, tocilizumab IV has been given to severely ill COVID-19 patients on a compassionate-use basis, without access issues for rheumatology patients. But in June, the Food and Drug Administration (FDA) approved this drug for emergency use (EU) and soon after the World Health Organization (WHO) called on Genentech and Roche, manufacturers of tocilizumab, to ensure fair distribution of its arthritis drug when used to treat COVID-19 patients in other locations. Actemra in the injectable form is not authorized for the treatment of COVID-19 patients under the Emergency Use Authorization. Soon after that, rheumatology patients would quickly learn their access to tocilizumab infusions would be short-lived.

“A couple of months ago my doctor said something that could potentially change my life forever,” explains Stacy (USA), diagnosed with Rheumatoid Arthritis at age 24, has successfully been treated with Actemra infusions since 2012. “He said, ‘Due to increased COVID hospitalizations, we have to switch you to a different medication.’ Shocked and angry, she burst into tears. “Before tocilizumab IV, I wasn’t able to function. My parents had to move in to help me with my own family, as I was unable to hold or feed my baby.” Not comfortable giving herself injections, she adds, “I’m terrified of starting over with a new treatment after 8 years of success.”

Deb (USA), was diagnosed at age 12 with Juvenile Idiopathic Arthritis (then called Juvenile Rheumatoid Arthritis), years before the first biologic DMARD was available. As a result, she has hard-to-treat (“refractory”) disease, failing 10 biologics. She was hopeful to start tocilizumab IV after the injectable was minimally effective. “I had one infusion before the shortage. For that month it was easier to get out of bed and I got more done around the house without my hands flaring. I’ve switched back to the injections and already needed days off to rest in between activities.” She has also had 9 surgeries on her feet, neck, wrist, and knee. Her husband administers her injections, as Deb’s fingers and thumbs are disfigured from long-term disease damage.

Sarah (USA), originally misdiagnosed with osteoarthritis at age 19, re-diagnosed with Rheumatoid Arthritis 20 years later, explains, “On weekly injections of tocilizumab, I felt terrible after 5 days. The drug wasn’t effective enough for me so my rheumatologist suggested it was time to move to the infusion version so we could increase the dose. So, we moved to infusions and felt great for about 27 days. I could

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4 https://www.rheumatology.org/Portals/0/Files/Guiding-Principles-Scarce-Resource-Allocation-IL-6-Inhibition.pdf
travel, get house projects completed, and help my dad move items to storage. I had my life back! Now I’m forced back on a version of the medication that we already know isn’t ideal. I was hopeful the infusion would allow me to fully function in society again, potentially keeping me off disability. Now what?”

This is a global issue

Thousands of rheumatic disease patients worldwide are being switched from tocilizumab IV to something different. Sarah C. (New Zealand), diagnosed with Rheumatoid Arthritis at age 23, had uncontrolled Rheumatoid Arthritis until she started this medication 8 years ago. She was recently notified that her next infusion, usually given every 6 weeks, was scheduled for August of 2022. “That must be a mistake,” Sarah told us. “Then I was informed that all future infusions have been canceled, there’s no more tocilizumab left in the country because they are using it somewhere else in the world for treating severe COVID patients.” (Referring to the FDA authorized use in the United States.)

“After failing other drugs, this was a miracle! Apart from some fatigue and mild pain, I could function well.” In New Zealand, switching to the injection form isn’t an option, so Sarah, a teacher, will start a new drug entirely - in pill form, taken daily. “I’m hopeful it works. If not, I don’t know what to do. I have no more sick days left, so any time off would have to be unpaid.”

The fear is real

Erin (USA), who has not yet lost access to her infusion adds, “Finding something that works is insanely difficult, but necessary for me to function in college. I’m a theater student, my position is physically demanding. I’ve tried doing this on medications that were not working well for me, and it was one of the hardest things I’ve ever had to do.”

Tried a few biologics prior Actemra and after a few months her disease still wasn’t controlled, so they switched to another biologic – and then a couple more – before going back to Actemra infusions because Erin and her doctor felt that it helped more than any of the other options. She has stayed on this medication for the past two years. The need to remain on stable treatment is essential for Erin’s health, as she already lives with numerous comorbid conditions.

With COVID cases worldwide rising and those unvaccinated representing the highest percentage of hospitalizations, these patients – and thousands like them – may have to continue dealing with unnecessary pain, anxiety, and risk long term health challenges.

It's not only patients who are fearful. The problem of mismatched supply and demand has been heightened by people and institutions hoarding the drug in response to access uncertainty. In time,
other medications will be approved for treating hospitalized COVID patients and the shortage may not be as severe. But, in the meantime, what can we do?

How can we fix this?

We are hoping those still deciding whether to be vaccinated will read this piece and consider the sacrifice thousands of chronically ill patients are being asked to give to ensure enough medication is accessible for those hospitalized. “We didn’t have a choice in this situation, but others can have a choice to help fix it. If more people would choose to be vaccinated, then hospitalizations would go down and supply would go up,” Sarah C. (New Zealand) says.

Deb (USA) adds, “I don’t think the public is aware this is a problem. Now that they do, I want to believe some currently not vaccinated may choose differently. There can be enough medication to go around if we come together and look out for one another.”

Another perspective

For one patient we spoke with who lives in the United States, the switch was a positive change. She did not want to be on the infusion form of tocilizumab, but her insurance would only cover the injection form. So when she learned she could have the injection at no increased cost, her perspective shifted from initial anger to a positive mindset, stating, “My original treatment may now go to someone whose life could be saved.” In this case, it’s a win-win.

This publication is intended to provide another layer of education for those still considering whether to be vaccinated so they can effectively make an informed decision. If you are not yet vaccinated and are considering it, please talk to your doctor to determine if vaccination is right for you. Learn more about this issue in the full article at www.AiArthritis.org/shortage.

Rheumatology patients forced to sacrifice their treatments to increase availability for hospitalized COVID-19 patients.11

11 https://www.gene.com/media/statements/ps_081621