

Navigating the Maze of Appeals Can Save Lives



Ginny Paulson
SHIP TA Center Director

We know SHIPs help people save money. In 2022, SHIP appeals counseling helped save someone's life. It is thanks to the efforts of Arizona SHIP volunteer Larry Spivack and Medicare expert [Mike Klug](#), who came out of retirement to usher this appeal to success. Mike said this was the most complicated, difficult, and rewarding appeal of his career.

An Arizona beneficiary named Ms. Mast suffers from [progressive diffuse systemic scleroderma](#). She had become gradually imprisoned in her body until she found hope and mobility from an experimental treatment: intravenous immunoglobulin (IVIg) infusion. It was immediately effective, but also costly. Each infusion comes with a price tag of \$16,000, and she needed two a month. She received six treatments until, unexpectedly, Medicare denied the claims.

If Ms. Mast wanted to continue her infusions, which would be necessary for the rest of her life, she would have to pay out of pocket. Not being able to afford it, she stopped treatment, but she pursued her rights. Turning to her *Medicare & You* handbook, she saw the Arizona SHIP phone number, and that's how she found Larry. Quickly realizing the complexity of the case, Larry contacted Mike Klug.

There were many moments when Ms. Mast, Larry, and Mike were nearly without hope. It was baffling that medical necessity wasn't abundantly clear in this case. The stated cause of the denial – a local coverage decision (LCD) – necessitated a journey down the path of a little-known appeals process and an even less-known national coverage decision (NCD) appeals process. Mike said, "The HHS' notices and correspondence in an LCD complaint are daunting for beneficiaries. Their content presumes that an aggrieved party is represented by legal counsel. Larry and I were both surprised

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by the high degree of formality, length of the notices, and use of technical legal terms that overwhelmed our client.”

All the while, the clock was ticking, and Ms. Mast’s symptoms were worsening. She wrote in her LCD appeal, “At many points between July and December 2021, I felt that I was dying. Most of the time I was lying flat in bed, feeling as though I was living in an inflexible shell encased by masking tape...Between January and March 2022, the 6 IVIg infusions turned things around for the better... To a remarkable extent, I [had] my life back and [felt] hopeful for the first time in a long time. Dr. Griffing and I credit the dramatic improvement in my clinical indicators to the benefits of IVIg. There is no other rational explanation for it.”


After months of sleuth work and going down three separate appeals process pathways, a request for reconsideration yielded the previously veiled reason for the original denied appeal. The Mayo Clinic doctor’s letter detailing medical necessity had been inadvertently omitted from the provider’s appeal on Ms. Mast’s behalf. In fact, Ms. Mast didn’t know that Mayo had appealed a denial on her behalf until Mayo lost the appeal.

A September 30, 2022, letter from Noridian ruling in Ms. Mast’s favor stated, “Thus, Ms. Mast has immediate and permanent relief in this matter.” Everyone involved breathed a sigh of relief at that statement. The doctor responsible for Noridian’s ruling, Dr. Fred Mamuya, called Ms. Mast personally to give her the news, saying she would never have to go through this again for her treatment.

Ms. Mast resumed her monthly infusions in November.

Thanks to the efforts of many, especially Dr. Griffing, Dr. Mamuya, Larry Spivack, Mike Klug, and Ms. Mast herself, more than quality of life has been restored. Faith that “the system” can care has been restored. As government-funded programs, SHIPs are also part of the system. Larry Spivack is a hero in this system success. This is not the first time that Larry has worked on a local appeal with national impact, and we can’t thank him enough, let alone pay him. As a volunteer, Larry said that he gets paid in “God bless you’s.”

Mike Klug is also a hero in this story. As you may know from the [July Medicare Messenger](#) article that details other Larry and Mike success stories, Mike has cancer. He wrote on his CaringBridge site, “One positive aspect of a cancer diagnosis is that it helps clarify one’s priorities. In other words, it helps me assess what I want to do, what would be nice to do, and what I can’t or won’t do. So,



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what do I want to do? First, the list included a Medicare appeal for a woman who needs intravenous immunoglobulin (IVIg) infusions to treat systemic scleroderma, a deadly rheumatoid condition. Medicare initially denied payment for the infusions. We challenged the denials and learned on October 3, when a medical director for Medicare called our client, that we succeeded with the appeal. It was a big win for the State Health Insurance Assistance Programs (SHIP) with which I've worked for many years, and we're all delighted with the result. Tick that off the list!"

The lessons learned from this case are still being collected. These lessons, along with tips for SHIP counselors, will be the topic of a March *Medicare Messenger* article.

Meanwhile, if you have a client with progressive diffuse systemic scleroderma, keep this success story in mind, and reach out to the SHIP TA Center for help. When we asked Ms. Mast why she was willing to spend time meeting with us to gather lessons learned from her case, she said wants to help other people in her situation. This terrible disease is growing, and Ms. Mast wants to make a difference. ↗

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– Mike Klug*



Mike Klug and Larry Spivack (2019)