In response to the fact that Medicare is considering limiting coverage for opioid dosages for pain patients, I am compelled to provide information from my personal observations. In this case, as in many others, it is literally a matter of life and death.

In July of 2002, my daughter experienced a catastrophic, one-in-a-million injury when her doctor ordered the administration of medication into the epidural space for both the lumbar and cervical regions of her spinal canal. Suddenly, without warning or explanation, she experienced the sensation of having been struck by lightning as unbearable, searing and lava-like pain permeated her body causing her to scream out in agony that did not then, nor has it ever gone away.

It was a full week after the injury that she was told the procedure went terribly wrong when the epidural needle transected her spinal cord at the C5/6 level. Little did we know then that the nervous system would be forever harmed and her pain and other symptoms would only intensify and become intractable.

Then and to this day, in addition to the unimaginable pain she experiences at all times, the damage to her nervous system causes innumerable other sensory torments. Among the manifestations of her distress are loss of sensation to many parts of her body, unbelievable pressure in her head (squeezing, emergency need to lie down), never ending chronic insomnia and sleep deprivation, myclonic convulsive-like jerks, as well as many others. Sensory input at every level is heightened to such a level that the sound of a distant lawn mower is so amplified it feels to her to be in the same room. Sunlight contributes to the over stimulation of her nervous system, as does normal conversation or activity in the next room. All environmental input is magnified to the point that her body is under constant attack, at war with itself.

According to Forest Tennant, MD, DrPH of the Veract Intractable Pain Clinic in his publication The Intractable Pain Patient’s Handbook for Survival, Copyright 2007:

*“Chronic pain, by standard medical definition, is a pain that is present over 90 days, and which can be continuous or intermittent. Millions of people have chronic pain. … However, true intractable pain (IP) is constant, severe, disabling pain, which causes changes in pulse rate, blood pressure, and adrenal hormone production. This form of pain is relatively rare. Control of IP requires the daily use of prescription medication. I estimate that one IP case occurs among about every thousand chronic pain patients.*

*“IP patients all require a custom-made, one-of-a-kind treatment plan. Most physicians and other medical personnel you encounter may be bewildered and even fearful of your treatment because they may not have encountered another patient with your pain severity.”*

My daughter’s pain is classified as “intractable.” Back in 2002, we were very hopeful. Even through the years of learning just want her injury meant, we’ve remained optimistic in the belief that there will come a time when her health will be restored and she can return to a point of living and enjoying her life.

Through trial and error, she and her pain specialist have established the most successful combination of medications to relieve the symptoms caused by the damage to her spinal cord. The most integral component of this combination of medications includes opioids. Although not eliminating it, opioids contribute more than any other medication to quiet her nervous system, lessening her pain to a slight degree for a brief interlude and to some extent keeps her head pressure at bay. It facilitates sleep and enables her to get out of bed for short periods of time so that she can accomplish something. Opioids serve as a means of rescue to my daughter, providing a form of temporary tranquility to the constant “firing” of her sensory nerves. I am not exaggerating in the least when I tell you that she will not survive without them.

Additionally, the letter and intent of the Medicare Modernization Act of 2003 that established the Medicare drug benefit was “… to bring improved health care and increased financial security for older adults and people with disabilities.” Disallowing coverage of opioids conflicts with the language and intent of the Medicare statutes.

Each and every day is a struggle for a return to health to pain patients which not only deprives them of a “normal” life, it also wears away at their the will to live at all. Depriving access to adequate medication removes the single most effective tool that has been available to them in combating the horrendous, never-ending suffering. It further restricts their quality of life and ability to function, limiting their ability to continue to strive for health.

Understanding the need to address the opioid addiction crisis in our country today, I urge you to recognize that there are two diseases affected by this crisis. Besides chronic addiction, I respectfully and urgently request that you consider the essential role of opioids in the treatment of chronic intractable pain. You must reserve the right of patients and their doctors to determine what is appropriate and retain final approval of this determination to the doctors not the insurance carriers,