

Dear Ms. Topper:

This is our story, our life. I would not wish another person to deal with this terrible tragedy. My daughter Melissa was a very healthy child until the age of fourteen. Then her life as well as mine changed forever. Melissa began having intense pain in her sides and flank area. The pain was so severe that at times while in the hospital the nurses would put her in a room at the end of the hall and close the doors so other patients could not hear her screams. After many medical, as well as psychological tests and stays in the hospital she was diagnosed with Loin Pain Hematuria Syndrome. This is a very rare syndrome that causes intractable pain in the kidney. The blood vessels spasm in the kidneys all of the time.

The doctors say it is like a person passing a kidney stone, however the pain never stops. There is no cure for this only pain control. Melissa would not be alive today if it were not for proper pain management. She is on disability and will never be able to work. She has an intrathecal infusion system implanted into her that automatically delivers a controlled amount of Dilaudid into her spinal column for pain control. Before this procedure was done she lived in the hospital getting Demoral injections. At one point I was sent home with her and had to learn to IV push Demoral for pain control. Several times Melissa has tried to kill herself because the pain was so bad. I would listen to her scream for hours begging to die, to stop the pain. My husband walked out. We lost our home because I could not work. She could not be left alone because she was so sick. At one time the doctors said she would have been better to have had cancer and died because then there would be an end to her suffering and pain. It was so bad at one point I prayed she would die to end the suffering. Thank God for good doctors.

Five years ago the pump was put in. Melissa is doing very good now. At times she has breakthrough pain, but the pain is controlled. She is now 21 we live in Florida. I have been able to go back to work, buy a home and go back to college. Please understand that there are people in the world who really suffer and are not just seeking these drugs for a high. They must have them to live. Without the medicine Melissa gets she would not be alive today. Two weeks ago she was able to go to the Prom with her boyfriend. She never got to do this because she was so sick to even attend school. I cried tears of joy to see my beautiful daughter be able to do something that I never thought she would even live to do. Please try to understand what we have been through and still continue to deal with every day. I have learned to be thankful for every good day my daughter has, because I will never forget the bad ones. There are real people in this world who suffer from real pain so bad it is hard for most people to understand or even comprehend. My daughter is one of these people. I hope and pray you never have to deal with a tragedy like ours. Thank you for taking time to read our story.

Pamela May
Melissa's Mom

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