



# Thank You!

*Here are the messages that Former First Lady Donna shared at the June 3<sup>rd</sup> Knights of Columbus benefit for the Kuchmas Family.*

## *Bill's Note*

My Dear Brother Knights and Ladies,

I am sorry I can't spend the whole day with you.

I want to take this opportunity to thank our Worthy State Deputy, Worthy State Officers, our Worthy Supreme Insurance Agencies and all of you for what you are doing for me and my Family.

I want you to know, I miss attending Council Meetings, Chapter and 4<sup>th</sup> Degree Meetings, State Council Meetings, State Conventions and Supreme Conventions, but most of all, I miss you.

In conclusion, I love all of you and I ask God to Bless you and your Family.

Thanks again,  
PSD Bill Kuchmas, III

## *Donna's Note*

Hi, Good Afternoon,

Wow! For the second time I am speechless!

Words cannot express how our whole Family feels about all of you being here today and those that couldn't acknowledging their regrets that they couldn't come. We are overwhelmed and so touched to say the least.

July 18, 1991 and Feb. 21, 2017 are two dates that changed our lives around. The July 18 date was the day Scott and Mark were diagnosed with Friedreich's Ataxia and Feb. 21 was when Bill was diagnosed with ALS. Scott's and Mark's disease comes from a recessive gene that Bill and I have and Bill's disease is 10% hereditary. You see Bill's Mom was diagnosed with ALS and she died on his Birthday.

What are the chances of having 3 neuromuscular diseases in one Family! Well, in our Family we are devastated and we also feel Blessed. The saying God doesn't give you more than you can handle. Well, God must think I am Wonder Woman 2. I don't wish harm to anyone else, but could we get a little break, God? He answered, I brought all these people here for you to shower you with love and support and prayers. And Boy did He ever!

People ask how do you do it? I do it out of love of God and my Family! Oh, don't get me wrong, there are times when I just have to cry to get through it, but once I cry and stop feeling sorry for myself, I pick up the pieces and feel stronger inside. It releases my tension, but I would not be able to do this without all of you and your love and prayers.

It has been a challenging road, to say the least, but I keep the whatever I can to be as normal as possible. Normal, that is, to our Family. You have to keep your sense of humor. For instance, we talk about poop a lot! Get them prepared for it and tell them to have a blast! My favorite is helping the Kuch to drop his drawers and say look, no chocolate mess! He just laughs and laughs because he thinks I am funny. He tells me all the time, you think you are funny! I said sometimes and you do too. Scott bought Mark and him a cup that says Coffee makes me poop. Scott even has a shirt that says I pooped today!

Bill has taken over my computer chair. I am so lost. I had to write 3 checks for some bills and he said to me did you write those checks yet and I said when you get out of My Chair! You can't do it on the dining room table? No, I think better in front of the computer and sitting in My Chair. But I will gladly share it.

I was talking to Andy Bauer one night and I told Andy that he and Bill have to have a race up the stairs. We both have stair lifts now. If I may, I would like to recognize the man who helped us get our lift and that is Former City Councilman, Nick D' Adamo. We can't thank him enough for all his phone calls, what can I do for you, your visits to not only Bill, but Mark in the hospital. I use to hold my breath when Bill would walk up the steps. He would take his right hand and take it off the rail to lift his left hand up on that side of the rail, standing on the top step. I had to turn the other way every time. I was so afraid he was going to fall. My stomach left me so many times seeing this. Thank you again, Nick, for your love and support for your German/Austrian Brother. Inside joke!

I want to share a day in our home. We wake up to the Kuch's alarm at 9:30 for his pill after taking off the bi-pap. Then we go to the bathroom for his relief, then we get Bill dressed and go downstairs to the computer chair, put the nebulizer on. I go in to see what Scott wants for breakfast. Then I check with Mark and most of the time you would think it was a restaurant because they all want different things. I fix their breakfast as fast as I can and while that is cooking on the stove, I go in and take off the nebulizer and get Bill's choice for breakfast usually a waffle, but sometimes he changes it. I give Mark's breakfast to his caregiver and I go feed Scott. If I am lucky, I may get breakfast or a cup of coffee. Then Bill gets up to go back upstairs. I ask him where are you going? He says upstairs to get away from you. As he is riding the chair up, I will say first floor lingerie, second floor sports department, and he is laughing all the way up.

We have a hard time communicating because of his speech and we play charades a lot. I go and touch my ear and say sounds like and he starts laughing. I make him laugh all the time because that is the best medicine. Then the games begin. His first text is always so polite. When you get done eating, bring me the paper. I reply ok. I take a couple of bites if I am able to get food and get another text. Bring my ice water too when you come up. I reply ok. Then I get a couple more bites and there goes the phone again. I look at it and he texts I want my bi-pap on too. Then I try to straighten up the kitchen after I am lucky to eat and go up to bring Bill his requests and then I get dressed. I am getting dressed and here comes another text. Get me up at 3:30. I reply ok. I go downstairs and then Mark wants lunch and Scott would like his leftovers. So I get Mark's lunch and if his caregiver is there, he feeds him and if not I feed him. Then I go into Scott and feed him if his caregiver is not there. Then Scott will ask what is for dinner? So I tell him and go start preparing it.

I didn't tell you about all the calls Mom, Mom, Mom, from Scott and Mark. I tell them I am changing my name to Dad. Then I get the text, get me up now and get my pills. When I am done feeding whomever, I get him up and give him his pills. Then supper is done and I feed either Scott or Mark and Confidence feeds the other. Oh, I get Bill's one hot dog with mustard cut up on the plate with 6 french fries cut in half with gravy and a spoonful of green beans.

Then I get to eat dinner and there it is again, a text saying bring me some ice water when you are done eating. Then I put the dishes in the dishwasher when I am done if I am lucky. I may have to go to the store to pick up medicine or a couple of items. I had to go to 3 different pharmacies the day Mark came home from the hospital because they didn't have them. Then I get texted 3 times, it doesn't take that long to get medicine. I am gone a total of 35 minutes to two different places. Hurry up. The other day Mr. Joe Allegro, who graciously comes to our house to cut Scott's and Mark's hair was coming. I also got my haircut that day at 2:45 and I was supposed to text Bill when I was done. I had to go to the bank and get 3 items at the grocery store and medicine. So I texted him at 3:40 and said I just got done. Bill texted me back, it's about time. It wasn't even an hour. Then I got another text before I got to the bank, you better hurry up, Mr. Joe is coming. It was 4:08 when I could pull over and reply he was coming between 5 and 5:30. I think he loves me that is why he texts me so much!

Then you would think the kitchen is closed. NOT IN MY HOUSE! Then it is snack time. Get their orders and fix it and feed one of them. Then at 10 p.m. the caregiver leaves and you hear a duet. MOM! MOM! And then the third one chimes in with a text to bring up some ice when I

come up. Which one do I tuck in first. I take turns or the one who is the most urgent or the one who isn't pooping. Yes, at that point I am by myself with triple duty. Then you get the text when you come up I have to take my pills. I reply ok. Get one done and go to the other. I try to get Bill done at 9:30 when he takes his pills. You have the routine with him of pills bathroom, fill the well for the bi-pap, put the mask on and tuck him in. Go back downstairs and it is usually Scott that is waiting. Give him his insulin, give him a snack so he can swallow his pills, drinks a little water, gets tucked in too, set up the tool box for his remotes, get the bowl with a snack in case he wakes up and his sugar drops, set the cups in the tool box and make sure the catheter bag is empty and read the weather report to know what Scott wants the temperature on the AC or heater, put the ceiling fan on 1, 2, or 3 speed and turn the lights out and say Good Night God bless you and I love you. I then go to bed and say my 3 rosaries so I can start another day.

In between I can throw laundry in the machines and switch them and then clean something besides dishes. Look at the mail and throw it on the table so it can pile high. So, you see, if you didn't send those prayers our way, I would not be able to do this. I just pray that God will give me good health so that I can take care of my guys. It is a struggle and a new challenge every day. I try to look ahead to make it not so challenging for them. If it wasn't for my Faith in God and all the love, support and prayers from Family and Friends, I wouldn't be able to do what I do. Oh, and about the poop, I am going to be the queen of the clean up! It never fails it is when I am by myself, but what is one cheek to another!

Thank you all again, from the bottom of all our hearts, for coming here today, showing your love and support and bringing joy to this man who thinks the world of you all. Whatever Bill did, it always involved the Knights of Columbus. We would have repair men from Comcast or Sears come to our house and he would ask them if they were Catholic and they were in trouble if they were. He would give them a speech like there was no tomorrow. He devoted his life to the Knights of Columbus. Our sons loved going to the Supreme Conventions in a different state when we were able to go. You made this day so special for Bill and you touched our hearts with your love.

Thank you and God bless you all!

The Kuchmas Family!

Bill, Donna, Scott, Mark, Billy, Jen, & Frankie.