

To: Health and Government Operations Committee
Madam Chair, Madam Vice Chair and Committee Members

From: Twila Bridges, Mother & Biggest Advocate for My Son - In Memory of Joseph S. Hall Jr.

Re: Testifying In Favor of House Bill 983 / Nursing Homes – COVID-19 – Visitation / Support

For 40 years, 8 months and 7 days, I've had to overcome adversity, fear, being apprehensive, unease, worry, and anxiety while at the forefront giving unconditional love and being an Advocate for my son, Joseph S. Hall Jr. As a result, I have had to make tough decisions over the years up until his death on April 30, 2020. On this day at 10:33am EST I witness my son take his last breath through zoom on a tablet at UM Laurel Hospital. He had resided in a nursing home for 24 ½ years.

In August 1979, I gave birth to my first born and it was not an easy birth. The first four years Joseph was progressing as a normal child. I had high hopes of going to his little league games. September of 1984, his life took a turn in a different direction that I was not prepared for. He started kindergarten. In the first few months his teacher noticed he started to lag the children in his classroom and became very frustrating for him. The Social Worker pulled me aside and recommended that I take Joseph to Children's Hospital for further testing while the school system decides what to do with him. It was obvious something was wrong with my child. At the Genetic Department there was a doctor who returned from England completing his internship and came across a child displaying the same symptoms as Joseph. He immediately started testing for the Mucopolysaccharide Disorders. The morning of March of 1985 I received the results and our life changed forever. He was diagnosed with Mucopolysaccharide Sanfilippo Syndrome Type C. There is a continuous process in the body of replacing used materials and breaking them down for disposal. Children with Sanfilippo Syndrome are missing an enzyme which is essential in cutting up the used mucopolysaccharides called heparan sulphate. The incompletely broken down mucopolysaccharide remains stored in cells in the body causing progressive damage. Babies may show little sign of the disorder, but as more and more cells become damaged, symptoms start to appear. Our journey began.

Mid 1985 the school system moved Joseph to a Special School. In 1992 Joseph would stay up for days no sleep. I was receiving in-home assistance for four hours a day Monday through Friday. In 1993 my insurance decided to cancel the in-home service. Even though he was regressing with this disorder my insurance stated I would have to go through the repeal process. The Board of Education for Special Education placed my son in a long-term residential program at Woods Services in Langhorne PA from 1993 to 1995. My heart was torn. I traveled the turnpike every weekend and need be weekdays for two years. In 1995 I sat in my office early morning and asked God to show me the way for my son. Joseph took sick and I took him back to Children's Hospital in Washington DC. Then doors started to finally open for him and he was able to receive Medicaid. I wanted him in the home, but his Genetic Doctor explained to me I would never receive 24-hour care for my son at home. Joseph had gradually started losing the ability to walk, talk and eat. The best setting to receive this type of care is in a Nursing Home. Late 1995 he was moved to Crownsville Nursing Home, Crownsville MD. He stayed there for two years and got sick again, hospitalized for six months and stayed at Hospital for Sick Children. Once stabilized I had to find another nursing home. October 1997 he was transferred to at the time Mariner Health that is today Patuxent River Health and Rehabilitation Center. He was a resident at Patuxent River Health & Rehabilitation Center in Laurel, Maryland for 24 ½ years.

I thought I had experienced a lot over the years advocating for my son but when COVID-19 overcame our Country, State and individual patients residing in a nursing home broke my heart. Every hospital visit whether short or extensive stay I was by my son's bedside 24/7. You see I was Joseph's voice, champion for his quality of care, dignity and respect related to his care. I had to go into overdrive, make sense of

this pandemic, stay connected to the media, CMS weekly updates that was constantly change, The National Consumer Voice for Quality Long-Term Care, 1st and 21st District updates, PG County Executive, MD Governor, MD Senator and Congressman Town Hall meetings and PG County Health Department weekly updates.

On March 10th Joseph care plan with his doctor and nursing home staff concluded his health was deteriorating and at this point all we could do is to keep him comfortable. On March 13, 2020 the announcement of the doors at the nursing closed to family members' shattered me because of COVID-19. I cried and feared for Joseph. It was my youngest son who reminded me "mom keep the faith" because you are a God fearing woman. At that point in discussion with the Administrator, Nursing Home Medical Director and reviewing the March 13th CMS latest update that my circumstance with my son falls under the exception for certain compassionate care situations, such as an end-of-life situation. I had to follow the CMS protocol entering the building required temperature check, social distancing, isolated to just my son's room, mandatory face mask, gloves, handwashing, sanitizing his area. I even isolated myself at home from my immediate family for extra precaution and safety for Joseph. The facility COVID case started with a staff in mid-April 2020. Then families that I was close with communicated April 20, 2020 two residents test positive for the COVID-19. When I visited Joseph on the 21st that evening, I noticed he was burning up and I immediately notified the nurse to check his temperature. His Nurse Practitioner was present and she immediately ordered an X-ray along with starting Joseph on an antibiotic. The facility did not have the antibiotic in house and we had to wait on the Pharmacy to deliver but he never received a dose. Unfortunately on the 22nd the x-ray results confirmed Joseph lungs did not look good compared to the last one conducted 30 days prior. His doctor ordered to send Joseph out immediately. With Joseph health already declining and now the COVID-19 diagnosis by the UM Laurel Hospital on the 22nd, I felt hopeless for my son. This was the first time I could not be by my son's bedside guide the Doctor's and Nurse's how to communicate and care for my son since he was not able to tell his story. I sat in the Hospital parking lot waiting for the Emergency Room staff to call me. They never did but being persistent I called them. The next day the hospital wanted to send Joseph back to the nursing home. Stating his temperature at 99.8 was a stable temp. I explained to them Joseph is not your normal patient. What is stable for you and I does not mean the same for him base on the nature of his terminal illness. It was the support I received from Delegate Joseline Pena-Melnyk, Dr. Trudy Hall, his Primary Care Doctor, and SavaSenior Care Management Team, Joseph did not get discharged. After speaking with Nursing Home Management Team, his Primary Care Doctor my decision for Joseph was not stable enough to return and would put him in unnecessary risk to his health. He struggled with his breathing issue, J-G-tube burst, needed replacement as a result no way to be feed or receive medication, was in a lot of pain along with his temperature fluctuating throughout the weekend. That Monday the 27th the Head Nursing discussed with me that Joseph condition worsen and my DNR preference for him. He would not make it through the end of the week. Through it all during Joseph hospital stay the nursing unit allowed me to have 24/7 Zoom access at my son's bedside so that he could hear my voice, comfort him and communicate with the staff. Joseph fought to the end April 30, 2020 and received his "wings" at 10:33am EST. I was deprived of being by his bedside but the last voice he heard was his mother. That I will cherish forever.

I am in favorable of this bill for residents in a nursing home that deserves a love one by their side for "Compassionate Care" or "Personal Care" visit. No one wants to be alone in their final hours.

Thank you for your consideration of HB983. I urge a favorable report.