

## **MATTHEW JAMES JONGEWAARD**

**06/01/1979 – 09/16/2020**

**- A Memorial Narrative -**

On the first day of June, 1979, a poor and unwed teen girl from North Carolina's low country gave birth to a little boy for whom she had no means of support. A girl friend's parents, already in their sixties stepped forward and offered to adopt the little guy who his Mom had named "Jamie." The prospective parents took the infant from the hospital with no warning or awareness that the enlarged circumference of the child's head should have been waving red warning flags at the medical staff. Clearly the newborn was an immediate candidate for shunt surgery to relieve the damaging build-up of fluid pressure within the brain. Had this not been overlooked, the insertion of a shunt would have created the possibility of a "normal" life. Tragically, this was not to be the case. Jamie was taken home to a preadoption waiting period of six months, a period of time in which he received no post-natal medical care. When the social worker arrived to finalize the adoption, she was left aghast by his very evident hydrocephalus and informed the prospective parents his condition presented a medical emergency. A shunt was installed. By virtual days, his life was spared, but the awful damage was done. A neurologist years later would reveal he had never seen a worse brain scan. The prospective parents were warned little Jamie might never progress beyond a vegetative life. They grieved, but acknowledged they could not deal with such a prognosis. As a result, Jamie restarted life as a ward of Howell's Child Care Center, a residential support center for the profoundly disabled in nearby LaGrange, NC (Now the Bear Creek Unit of RHA Health Services).

During Jamie's sojourn at Howell's, a young Maryland pastor and his Seminarian wife with two thriving elementary school age children had begun an exploration of a special needs adoption. The decision was faith driven with the conviction that we are "blessed to be a blessing" and rather than growing their biological family, they could reach out to nurture someone who might not otherwise find a home. Social workers turned down their initial urge to adopt a child of color because their suburban congregation and neighborhood had few persons of color with whom an African American child might identify. Their attention was then directed toward the physically handicapped. They took the Baltimore County adoption class and began perusing the loose leaf binders picturing and describing children with special physical needs. A tiny boy with a winsome smile living in a child care center in North Carolina caught their eye. And the rest is history as they say.

It is true that when they first appeared at Howell's, doctors presented them with a grim prognosis and their first night at the center prompted tears and second thoughts. Jamie, at just under two years could neither support himself on hands and knees, let alone crawl, nor could he speak any words. But he could smile and laugh and had a bad habit of biting his arm to vent anxiety. But the social workers and nurses sequestered the couple and their two children and chatted up all Jamie's potential: "Of course, he'll walk and talk, just you see. He's making such progress already. He is the star of the center. His eagerness and cheerfulness are so special, he lightens all our loads." The Jongewaards—David and Faith, Nathan and Rebekah—reached a family consensus: This child was destined to be their son and brother whatever may come! As it has turned out, that choice for life was never regretted and was only a source for gratitude as their horizon for love was expanded beyond anything they might have imagined. And yes, there were many, many trials and traumas as together the family weathered the storms and multiple surgeries and hospitalizations and attention and time demanded as this new member of the family developed and became an integral part of each of them. Gratefully, the

Presbyterian Church's health insurance for its pastors didn't even blink at his million dollar needs from his preexisting condition. And along the way, the subject of a number of shunt surgeries, he even had the skills of Dr. Ben Carson on his neurosurgical team at Johns Hopkins.

On that initial trip back to the parsonage in Baltimore County, at a restaurant along the Interstate, Jamie stunned with his first word as he enunciated distinctly, "cracker." After that, it was hard to stop the flow of verbiage and bartering. By five, he was walking with a fearless vigor coupled with the characteristic lurching of Cerebral Palsy, so determined that one time he launched off the three foot high stage in the church fellowship center. He survived that adventure at the cost of a tooth. The nurses' optimistic hopes were all happily confirmed from Day #1. A consolation note from a former parishioner mentioned being riveted with emotion the first time he marched down the church's long center aisle to the chancel as the acolyte to light the chancel candelabra. When the Jongewaards arrived home, they were greeted with a banner prepared by the beloved community of the church, "Welcome Home, MATTHEW." The Jongewaards retained "James" as his middle name, but, to mark his adoption into his new, forever family, they called him by a new name with which he was then baptized. "Matthew"—It means "Gift of God", a truth any who know him have always celebrated with thanksgiving!

Yes, Matthew knew he had special needs that restricted his possibilities and, no, he didn't know that. Crippled, with advancing vision impairment, a vast gap in educational achievement and an overbite that prompted disbelief in how he was able to eat and speak, he negotiated the world with amazing aplomb. Matthew attended school until high school graduation at the age of 22—through a variety of mainstreamed and special ed classes and schools, whatever was most in vogue at the time for those with special needs. He had a knack of joking around and teasing nearly everybody with a regaling humor that never intentionally offended. His affable nature was like honey to a bear. And he did have a special charm of learning and remembering the age and often the birthday of even the most casual acquaintance. His tested IQ was abysmal, but he could rock you with very perceptive questions and a vocabulary beyond his apparent ability. He played an astute game of Yahtzee, reasoning through his moves with an apt knowledge of the game. His facility with numbers did not extend beyond primal addition and subtraction but it gave him such satisfaction that he would occasionally confide his dream to go to college in order to become a math teacher.

Matthew grew up in the loving fellowship of Presbyterian churches—Chestnut Grove in Phoenix, Maryland; First Presbyterian in Ottumwa, Iowa; Southminster in Dayton, Ohio, as his parents were called to different congregations. Shortly after their arrival in Ohio in 1998, he had a massive brain incident. Once again doctors thought he was lost, but, as before, he was raised up again and teams of marveling physicians visited at his bedside to be high-fived by the recuperating Matthew. This trauma ended the use of his legs, and, relegated to a wheelchair, he moved from home to a group facility. But his abilities to talk and reign as the Yahtzee king prevailed. Along the way, he had participated in school plays and Sunday School and Church youth groups, sang in the church youth choir and was confirmed after attending confirmation class in the company of an adult advisor/sponsor. In 2004, when his mother was called to San Pedro Presbyterian Church in San Antonio, Matthew travelled to a group residence in San Antonio. One of his most devoted and "sitter" friends in Ottumwa, Iowa, Brian Diebold, later became a Presbyterian minister himself and was called to a church in San Antonio which allowed him to renew his childhood friendship with Matthew. Matthew was keenly aware of being a beloved child of God and loved to sing along with worshipful praise music on his CD player. He enjoyed music and movies and loved to anticipate what would come next as he had most of the lyrics and dialogue memorized from repetitive exposure. But he also relished fierce competition in making "guy sounds" with his closest friends (such as Brian) and family and, perhaps sadly due to his father's sole indiscretion on the "man trip" moving from Ohio to San Antonio, Matthew forever after wanted to go to Hooter's on his

birthday—a plea occasionally indulged by his group home staff. He basked in the attention given him by all the “hot” waitresses. It is however doubtful that Matthew ever fully passed through puberty despite living to become forty-one. He did, however, want to be regarded as a full adult and so considered it a badge of honor to be able to watch an “R” rated movie and on occasion of pain or indignity letting rip a foul word he had never heard at home unless perhaps on the sly from his older brother. When called on his inappropriate language, he was always contrite. It would be hard to detect a vile thought or mean deed in his behavior, though he would often remind his sister how, on a many years prior Easter, after consuming his Cadbury egg from his Easter basket, he had snuck into Rebekah’s room and consumed hers as well.

Indeed, among his appreciations of his brother, Nathan remarked how being a brother to a disabled person taught him that people who are different are yet fully human beings just like the rest of us. A college friend of Rebekah’s wrote in condolence, “I loved hearing your stories about Matthew because they made me want to be a better version of myself.” That summed up Matthew’s impact on all of us—whether we were family or friends or care givers in group homes, residential facilities, clinics or hospitals—we were drawn to him with affection and amazement, grateful to be blessed by his unaffected, natural graces. As a family, speaking now as his parents, we want especially to thank Odella Lee (“Trouble”) and Chrystal Abrajan at the Daybreak Group Homes for their exceptional love and care in guiding and protecting our son for more than a decade and then, from early 2018, the entire staff and many residents of the Blanco Villa Nursing and Rehabilitation Center for being such a caring support team. Finally, we single out PASSR (Preadmission Screening and Resident Review) for validating Matthew as qualifying for daily companionship. For 32 hours coverage a week, Lorraine McVey and Nancy Garza, came individually to be with Matthew, feeding him, playing endless Yahtzee games with him and in general being his advocate and compassionately looking out for his best interest. He became to these Christ focused women as their own son and he thrived in their company. Who knew the State/County had such an unimaginable resource available to needful Medicaid facility residents?! Matthew’s life is a story of gifts. He was our miracle son. It is all Grace.

The final grace was a nurse at Methodist Hospital named Candace who set up a zoom meeting for our entire family including the grandchildren to profess our love and say our good byes to Matt on Tuesday evening having made the difficult choice of palliative care as Covid-19 had destroyed his lungs beyond repair. Candace was his final loving touch throughout the night. Matthew slipped peaceably away with minimal apparatus at 11:07 the next morning.

Matthew is survived by his parents, David and Faith Jongewaard; his brother Nathan and sister-in-law, Kim Norlen; his sister, Rebekah and brother-in-law, Ian Nyberg; by his niece, Grace Nyberg and his three nephews, Oscar and Harry Jongewaard and Isaac Nyberg, by his grandmother, Eva Dow and by aunts, uncles and cousins. All who loved him grieve his death, as we entrust him to the mercies of God.

*“Whether we live or whether we die, we are the Lord’s.” [Romans 14:8b]*

[Due to Covid-19 distancing, A public Celebration of Matthew’s life will take place when family members are able to gather, likely in the summer of 2021. Anyone desiring to make a memorial gift are encouraged to send a contribution in Matthew’s memory to any of the four congregations that nurtured his life and faith:

Chestnut Grove Presbyterian Church, 3701 Sweet Air Road, Phoenix, MD 21131

First Presbyterian Church, 228 W. 4<sup>th</sup> St., Ottumwa, IA 52501

Southminster Presbyterian Church, 7001 Far Hills Ave. Dayton, OH 45459

San Pedro Presbyterian Church, 14900 San Pedro Ave., San Antonio, TX 78232

