

Living the Hard Times Out Loud

By Naomi D. Williams and Noah S. Williams

2014. A challenging, life-changing year
filled with sickness, hospitals, trauma.
Summer was a tailspin. Uncanny, unsavory.
Something was definitely wrong.



Together forever.

2009. Five months in NICU.

How could I know
what I was being prepared for?



Humble beginnings – Noah, June 2009

Noah had been diagnosed. So
lethargic, long stretches of sleep,
and utter unresponsiveness
were “normal.” They didn’t
see the cascade coming:
constipation, impaction, toxicity,
septic shock.



Shared decision making: Dr. Pipkin, Noah, and I
contemplating and discussing next steps.



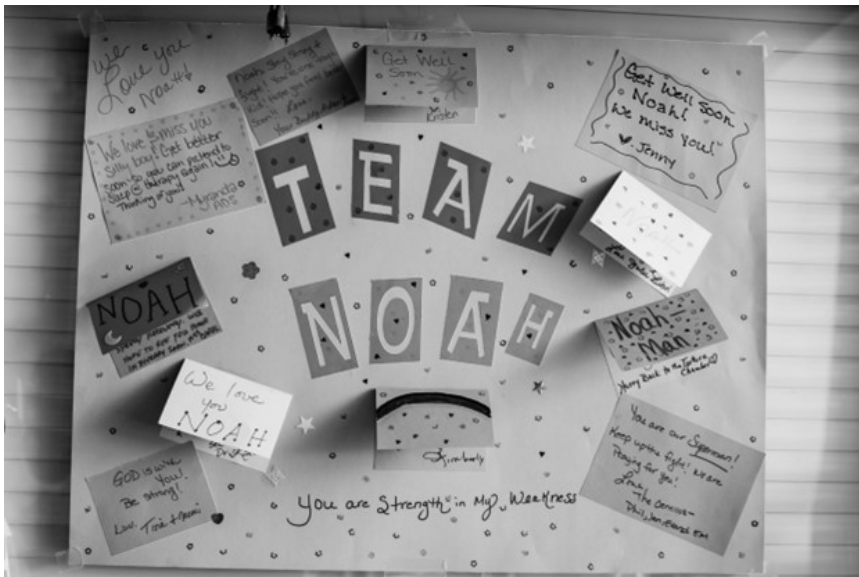
Swinging was his happy place.

“Normal” was a happy, mischievous
smiling boy. It took years of care,
collaboration, conversation and confidence
to help him get there.

And so much uncertainty. No one knew what was wrong. He slept. His body swelled. He was diagnosed again. No one knew what to do, but they came—family, friends—and sat with us on plastic chairs in intensive care. They brought food.



Not his normal.



Team Noah – Get Well Soon card.

Never underestimate the value of a real meal, home-cooked, hand-delivered—how it sustains the spirit and calls you back from the edge of despair.

Amy came. A dietician.
Only later did I know how loss
led her to her work, to church,
to me—sister, friend, and guardian
to Noah if he ever needed someone,
if something happened to me. If my family
couldn't care for him, Amy and Rob would.



Gates family (L-R: Sawyer, Amy, Rob, Robbie.)

Humor helped, and laughter.

“A cheerful heart is good medicine.”

They moved him. More room, more machines
dialysis ready. Again, big-hearted people gathered—
parents, speech therapists, physical, occupational
therapists, physicians, chaplains encouraging, enabling.

And even then, Noah smiled. He was ready
to spread his wings and feel fresh air.



All the pumps needed to provide the medicine his body required.



Mother and son.

Disabilities do not define this child.

They cannot be “fixed.” He does not
need to be. **The best that is in him**
keeps unfolding into the spaces
so many help open and hold.



Family time (uncle, cousin, grandmother, cousin, auntie.)

We are changed now. I hit rock bottom
in that hospital. Then I found
a new way to see and receive the life we are given
each day. **Each morning I remember:**
“Live your best life today.”

Our “normal” isn’t. But it’s ours.

Our bond is unbreakable. We are encircled
by people who rally and show up and know
how to help in hard times.

Our story matters. The pictures matter.
The memories matter. All of it
is becoming a gift for someone
we may never know.

This article is dedicated in memory of our friend, Evan John Luaghlin, who unexpectedly died on November 27th, 2018.



Evan kissing Noah at the 2015 Tri My Best triathlon.

About the Author



Naomi D. Williams is a mother on a mission to help families and caregivers navigate life with differently-abled kids. She believes individuals with intellectual and developmental disabilities can and should lead an

exceptional life. Naomi is a Life Doula and Hope Coach who supports individuals through major life-altering events. She has added author, grief coach, and yoga instructor to her toolbox, all tools that have served her well as an

advocate and navigator. Naomi has spoken on local, regional, and national platforms, making the connection and showing the interdependence necessary for raising a differently-abled child as a productive member of society.

When not advocating for her family or others, you can find Naomi getting lost exploring nature or taking a deep breath on her yoga mat.



Noah S. Williams is 13 years old and living an exceptional life. He was born a 26-week micro-preemie with a dismal prognosis for life. He is confronted with a multitude of obstacles daily, due to cerebral palsy, epilepsy, and visual impairment. Noah is a train wreck on paper, yet he is not that paper. Noah is a commissioned artist, endurance athlete, and public speaker. His work has been featured in the Autism Museum inaugural exhibition “Empower Being You” (May 2022), “The Body Has Its Reasons” (July 2022), and The Antidote Medical Humanities Journal of MCG (Vol.4, 2023). Noah is the main character in the published book series *Adventures in Noahland*. Titles include: *Different But The Same*; *Noah Goes to Camp*; and *Noah the Junior Ranger*. Noah is a principal in the *6,000 waiting* documentary released in 2020. Noahland Art came about in a truly unique way. Noah attended a local art camp. It wasn’t a special needs camp, so they adapted and modified a few things for him to participate and be among his neurotypical peers. The kids wanted to paint their national flag on a particular project, as an idea of their own. Each child told me what country they represented — “China,” “Israel,” and “the United States.” When we got to Noah’s flag, one of the kids said “It’s Noahland!” And thus, Noahland Art was born. Welcome to his “country,” where being disabled doesn’t mean less than, it just means different. It is a place where he refuses to be defined by his disabilities, yet embraced for his uniqueness. Noah likes to travel, spend time with family and friends, make people think past textbook knowledge, do pranks, and indulge his mom in trying new activities.