

THE DIFFERENCE MAKER



By Wendy Nadherny Fachon

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“So many people have come and gone through my life. My world has changed so much along with the settings in which I live and the people I share my time with. And this world of mine continues to change day by day and step by step. However, as much as it may change, my life is defined by the substances of its moments, by every interaction and exchange. And you have all played a part on this journey that is my life.”

Neil Fachon 5/8/96-2/19/17
social media post

This book is dedicated to the many who blessed Neil's life and carry his light forward. Your names alone could fill pages and pages.

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Knowing one's child becomes more challenging during the years of adolescence, that awkward transitional stage between childhood and adulthood. Teenagers tend to spend more and more time away from home, pursuing after school activities, playing sports, hanging out with friends and exercising their growing independence. For our family, dinner hour provided the best opportunity for us to connect, however, meal time rarely lasted more than a half hour. The kids would share some happenings and forget to share others. Then there were the events and thoughts they shared only with close friends – definitely not with parents. It is no wonder that we see our teenage children as enigmas - puzzles with missing pieces.

After Neil died, at age 20, I began the process of sorting through the memorabilia he had accumulated in the boxes, drawers and book shelves of his bedroom. This material includes artwork, notepads, notebooks, journals, personal letters and magic notes - things we would never have touched if Neil was still alive, because we respected his personal space and privacy. Now these items have become puzzle pieces begging for our attention. In fact, I sense an unspoken permission, even an urgency, to touch and look and read and savor these memories.

*These remaining memories have been an invitation to actively further our relationship with Neil's spirit. What has emerged from all this is a “coming of age” collection of stories unlike any other. The first story in this book, **Real Friends**, is the perfect introductory glance at this process of discovering, sorting and assembling the puzzle pieces, as well as searching for their meaning.*

REAL FRIENDS

Back in January 2011, Neil's high school science teacher, Mr. Rath, asked each of his freshman students to write a letter to themselves, to be delivered upon college graduation. Unfortunately, Neil would not live to read the letter he had written.

Over seven years later, in May 2018, Mr. Rath contacted Dean and me, told us about the letter and asked if we would like to have it. At first, Mr. Rath had hesitated to tell us about the letter's existence, fearing it might contain something we would find painful. On second thought, however, he thought *we* should make the decision about whether or not to read it. The following Sunday, Mother's Day, Dean carefully slit open the envelope and handed it to me. I read it aloud:

Dear Me,

By the time I read this I better be a billionaire mechanic top class with a chauffeur and lots of nice stuff. JKJK. But seriously. It better be better than where I am right now though, cause where I am now seems to be no friends, only Starcraft 2, Chess, in the fall soccer and whatever else I decide to do. My niche which is apparently the main thing I am supposed to be writing about, according to Mr. Rath, is small. I don't have much of a niche at school. I go I learn take notes take tests, move from group to group, talk from person to person without any real close friends. Sept Andrew, but you probably don't even remember him where you are somewhere in the future, Plus he changed schools to Hendricken so we can't hang much anymore. My niche at home is fairly small. I help with yard work; raking, shoveling snow, mowing the lawn, picking up sticks, minny

stuff nothing big. I just sit around playing Starcraft 2 all day. Which is probably going to cost me a bit, but hopefully it doesn't cost you wherever you are. Hopefully you actually got a girlfriend and a group of friends you hang with on Friday nights. People call you regularly and chat. I know I don't have it as bad as many others, but it would be nice to have friends to hang with after school that aren't complete morons. I hope whenever you open this letter you find it of interest and not a peculiar annoyance, because if you found this to be an annoyance that would kinda be sad to me. It would mean you'd fallen farther into a slump than you are now. Well enough of this riff raff. You probably gunna think you were crazy back when you was me.

Sincerely,
You

The text kept blurring before my eyes. I had to pause periodically to wipe away the tears. We were aware Neil's first semester of high school was a tough one, between soccer team hazing and disappointing friendships, however, it seems to have been tougher than we could have guessed. Neil chose to confide in us about some of his social challenges, because he needed *someone* to listen. At the same time, he was adamant that we refrain from becoming directly involved with his problems. We had to respect those wishes.

The day after Mother's Day, while taking my ritual morning walk, I found a battered book lying next to the sidewalk. It was titled REAL FRIENDS. I felt as if it had been thrown down from heaven, when in actuality, it was just a Hanaford Elementary School library book that had probably fallen out of an unzipped backpack. The timing was uncanny.

Both Neil and his sister, Evie, had attended Hanaford, which served grades 4, 5 and 6 in their time. Neil and his best friend Andrew were often bullied when walking home from school. Neil shared some of those incidents, such as backpack stealing, while asking us *not* to get involved. More serious incidents, which Neil chose not to share, I only learned about years later, from Andrew's mother.

Opening the book, REAL FRIENDS, I discovered a graphic novel that follows a girl through elementary school and tells of her problems finding and keeping real friends. The story was about groups, belonging, and suddenly not belonging. It reminded me of my own experiences at that age and the painful lessons of exclusion, cliques, fickle friends and bullies. As awful as my own experiences seemed at the time, much like Neil, I did not have it as bad as many others. In truth, Neil had a lot of good friends, however, during the middle of his freshman year, he was wondering where they all were when he needed them.

I began sorting through the belongings in his room and opened a storage box in which there were eight crumpled and flattened white paper bags. They were filled with all kinds of stuff. I was drawn to one bag upon which Neil had scribbled his familiar signature. I heard a bell jingle as I lifted the bag. I poured the contents out onto his bed: a pile of *magic notes*, a CD dated 2011, and a safety pin threaded with a jingle bell and a small strip of rainbow-striped ribbon. These were all souvenirs from Neil's summer after freshman year.

He was 15 years old at the time, and Dean and I had driven him up to Nichols College in Dudley, MA for SLTP camp. SLTP is the acronym for **S**tudent **L**eadership **T**raining

Program, and its five-day immersive experience was attracting teenagers from all around New England. Neil was greeted at the entrance to the dormitory by a student wearing a scarecrow hat, and he was assigned to the Scarecrow group. Another student appeared to help Neil carry his bags to his dorm room, and off he went, into the Land of Oz.

When we returned to camp five days later to retrieve Neil, he was smiling from ear to ear. There was much hugging and laughing and crying among his sixty new friends, as the SLTP campers realized it was time to leave one another and return home. On the ride home, Neil said little. He sat quietly in the back seat, reading pieces of paper he told us were *magic notes*.

Magic notes are affirmations campers write to one another at the end of the week. The small messages are personal and acknowledge a gesture, a conversation, or a shared thought that mattered. The notes are extremely special.

Neil had stayed awake during the entire last night of camp, taking a great deal of time and care in writing a note to each of his new friends. His favorite camp activities were exchanging magic notes and engaging in vaudeville. Regarding the latter, Neil reveled in the process of working with team members to create skits and perform them.

I sat down on Neil's bed and started to read through the *magic notes* from that summer:

Neil,

When planning for Vaudeville, I was frustrated when we couldn't get our 4th skit together. Then, you presented a single line (about the "game plan"). The fact that there was finally something set in stone about the skit made me feel so much better. Thanks for that and much more!

~J

Neil,

Oh my god you're Hilarious! You never stopped making me laugh even when I was about to pass out from exhaustion! You really contributed a ton of great ideas through the week like with Vaudeville. Some of your great ideas made a lot of our skits the best they could be! You were always so full of energy (even after the 3AM Party fest) and you never stopped coming up with amazing ideas that made our group the best we could be!

GO SCARECROWS!!

~S

Any guilt I may have felt in reading Neil's personal *magic notes* melted away. In my mind's eye, he was looking over my shoulder and smiling with me. I considered the double irony that he had been placed in the Scarecrow group. Neil was a thinker, with a good brain and a lot of good ideas. Then he lost his life... to brain cancer. I continued to read.

Neil,

It was great meeting you! You had a lot of good Vaudeville ideas for "satisfied customer." And it was really funny when you let everyone blame Neil!

~E

Four other notes mentioned Neil's humorous role in the skit about blame. I was amused to think that Neil had volunteered to play the *straw man* for the SCARECROW group. The term **straw man** generally means a person or an argument that is set up to be knocked down, usually to make a point.

Neil,

Your leadership footprint read "positive attitude"
- remember me commenting on your smile? Well
That's the best visual to show you that you use
this quality All the time!! Hope to see you back
next year! BIW! OOCIC!

Dear Neil,

I love how enthusiastic you are about everything,
your smile and energy are contagious! Stay
golden!
XOXO

~J

I was hardly surprised by the number of notes that complimented Neil on his smile. Smiling was one of Neil's super powers.

I *was* surprised by the number of notes that commented on the insights Neil shared about yin and yang. He loved the black and white yin and yang symbol, and enjoyed philosophizing about how opposite forces are actually complementary and interdependent – night and day, negative and positive, female and male...

Neil,

I LOVED your hat and achievement night poem about the yin yang. Seriously – that is my life symbol. I feel so passionate about the message of balance.

~G

P.S. – come back to SLTP!

Yang and yin... light and dark... life and death. The yin-yang symbol is rooted in Taoism, a Chinese religion and philosophy. I recall Neil learning about Taoism in a middle school social studies class, and the topic fascinated him. In Taoism, life and death act in harmony to maintain balance in nature. In nature, things that appear to “die” often can come back to life later on. For example, a tree that appears to die in the fall comes back to life in the spring. Taoism sees human death in the same way, claiming people “live” after death, too. In fact, Taoists believe the spirit lives on as part of the Tao after death.

In eighth grade, Neil had been assigned a ceramic arts project – to create a personal name plate. Measuring six inches in diameter, he designed his name plate as a black and white yin yang symbol. I retrieved the ceramic disk from where it sat next to Neil's stereo speakers. I brushed my fingers over the orange N and red E, superimposed in raised textured letters on the black half, and over the blue I and yellow L, recessed into the white half. I held the name plate in my hand and felt the physical weight of it, before setting it back down and returning to the *magic notes*.

Dear Neil,

I enjoy your yin yang thought about balance and how it needs to be kept. Lead on.

~J

Dear Neil,

I was diggin your sunglasses at the formal dinner and throughout the week, you made me laugh and I love how you kept getting very into the mind games.

~D

Neil Fachon -

love you and your personality. You are so funny and personable. You truly embody the sltp spirit. Sneakers with a suit are awesome. It is cool we live so close. Gotta love R.I. See ya. Keep in touch.

~L

One by one, I read the notes again and then placed them back in the white bag. I will never forget Neil, sitting in the back seat of the car, relishing his *magic notes*. By mid-summer, life was looking better for the boy who had written seven months earlier about having “no friends.”

As a parent, I was uncertain how to counsel my children with regards to faith. In other words, what could I do or say to help my son or daughter work their way through seemingly hopeless situations? Having grown to believe in a higher power, I would ponder how to teach my children to believe in a higher power? Were there ways of showing them as opposed to telling them? Showing is always more effective then telling.

I could show them, through my own living example, how I stay positive, and faithful, and persist in looking for opportunities that will help me out of trouble. I could also show them, through sharing stories of how I manged to solve my own problems. My experiences, asking for and receiving guidance from a higher power, often involved quirky coincidences. The appearance of the book, Real Friends, is a perfect example of this.

*During the fall of Neil's sophomore year, he and I took a trip together, where I was given the opportunity to “show” him some examples of divine guidance in the form of quirky coincidences. The following story, **Higher Intelligence** helped him to understand my unusual approach to faith and higher awareness. It was a shared experience that I hoped would help bolster his faith and help him to recognize there is always a “lighter” side.*

HIGHER INTELLIGENCE

Mid-October of his sophomore year of high school, I took Neil on a weekend adventure to Chicago to visit Grandpa Ferd and Grandma Ellie. As we walked through the airport toward the Baggage area, I pulled out my cell phone and dialed the limousine service Grandma had given me – 847-852-0007 – and asked for Yury. The voice on the other end of the line asked me to look for limousine number “double-0 seven” outside of the terminal building.

Sure enough, we found a car with the number 007 attached to the windshield. The driver stepped out and introduced himself, with a heavy Russian accent, “I’m Leo.” It felt as if we had stepped onto the pages of a James Bond spy novel.

Grandma and Grandpa liked using Yury’s limousine service to transport visitors back and forth to the airport. The last time they had ordered the service for someone, however, there was some confusion. Grandma had given a woman, who had been helping her take care of Grandpa, \$50 to pay Leo. When the limo arrived at the airport, however, the woman got out of the limo and slipped away without paying, never to be seen again. To stay in the good graces of Yury’s limo service, my mother planned to pay Leo the \$50 that was owed him when he dropped us off.

Neil and I settled into the back seat of the car, and the driver drove us out and away from the airport. As we sped off onto the interstate highway, I considered the facts of our situation and started to play a word game... Double-0-seven. Secret Intelligence Service. Yury. Leo. Grandma owing money. Grandma's name is Ellie... The seemingly random bits of

information jostled around in my head and reorganized themselves into a new semblance of order.

“Neil,” I said, “Ellie owes 50.”

“Huh?” replied Neil.

“Grandma owes Leo fifty dollars. Ellie owes fifty,” I said. Then I proceeded to lay out my wacky analysis, “Ellie is spelled LE in letter code.” I pulled out a scrap of paper and wrote some letters and numbers:

L E Os 50.

I continued explaining, “Our limo driver is named Leo. L E O spells Leo’s name, so Ellie owes \$50 translates into ‘Leo’s \$50.’”

Neil gave me a you-are-nuts look, as I wrote the letters:

Y U R Y

I said, “Look. Yury is the name of the man who owns the limousine service. See the letters U and R between the two Ys? UR among the Ys, and then I wrote: You are among the wise.”

Neil looked at the paper and replied, “YOU ARE completely nuts, Mom! How do you come up with these things?”

“I don’t know how,” I replied. Thinking back, I remember my third grade teacher, who introduced our class to homonyms – words or word combinations that sound alike, yet have different spellings – their, there, they’re. She made the learning fun by teaching us a homonym game. My fifth grade teacher stretched our young minds with Mensa puzzles. While

I rarely got the right answer, I was fascinated with the solutions when she shared them with the class.

What is **Mensa**? According to *Popular Science*, it is an exclusive society for individuals who score in the 98th percentile or higher on a preapproved intelligence test. What is intelligence? Intelligence is many things, including information gathering, logical reasoning, creative or critical thinking, and puzzle- or problem-solving.

When we arrived at Grandma and Grandpa's, Neil and I dropped our bags to hug Grandma as she stepped out the front door of their cottage. While she took care of paying Leo, Neil and I walked into the living room to greet Grandpa, who was seated in his favorite chair. I sat down on the couch across from Grandpa, and something caught my eye. It was a magazine lying on the coffee table in front of me. I gasped, not believing my eyes. The word "Spymasters" jumped off the center of the cover. The magazine was the latest issue of Grandpa's Yale Alumni Magazine. Underneath, in slightly smaller letters I read, "Three espionage novelists on what it takes to write a thriller." I held up the magazine cover for Neil to see, and he raised an arch eyebrow.

The following day, Grandpa invited me to attend vespers over at the main building of their retirement community. Vespers is a late afternoon service presented by a chaplain. A chaplain can be a minister, priest, rabbi or even a Buddhist teacher. Vesper, by no small coincidence, is the name of James Bond's secret co-agent in the book Casino Royale.

Neil remained back at the house with Grandma, while I walked over to the main building to attend vespers with Grandpa. I walked alongside him, as he drove his wheel chair.

Grandpa had played football in his college years at Yale. Through the years he suffered with back pain. In later years his spinal problems developed into neuropathy, a gradual deterioration of the nervous system that began with numbness in one foot. As the disease progressed, Grandpa reluctantly accepted the support of a cane, then a walker, and finally a wheel chair.

We entered the Vail Room and were handed a copy of the vespers service program. The sermon, being delivered by Reverend Andrew Rosencrans, was titled “The Art of Recognizing Angels.” On the cover was an illustration of “Peter and the Angel.” The first bible reading cited Judges 6, the story about Gideon and an angel that came to tell him he had been commissioned by God to lead the resistance. The second bible reading cited Acts 12, the story about Peter and an angel releasing him from his chains and sneaking him out of the prison.

The stories of Peter and Gideon coincide with some of the darkest times in history. Both men were acting against oppressive regimes, and in both instances angels stepped in to help. In both stories, these angels had not been recognized as angels until they vanished from sight.

The reverend stated: “Sometimes we come to moments of crisis when an angelic intervention is urgently needed – sometimes God is with us in ways we only recognize after the fact – and perhaps one of the ways God sometimes chooses to be with us is through the agency of something we call – for lack of a better term – a guardian angel.”

My ears perked up at the mention of the word “agency.” I imagined a secret agency comprised of angels and God sending an angel down to help Peter escape.

The reverend went on to define angels as messengers and to identify Peter himself as an angel messenger. Then he stated “sometimes we are called to be the angels that bear God’s message of good news to people in their own times of darkness and in their own moments of crisis.” He concluded his sermon by exclaiming, “Be an angel; let your message of good news be the light that helps dispel someone’s darkness; because the way God chooses to be present in someone’s moment of crisis, is through angelic messengers like us. AMEN”

The vespers service had been held in the Vail Room. Playing the homonym game, I thought about the word “veil,” which means to *conceal, hide or disguise*. We often talk about angels, hidden beyond a veil, yet keeping watch over us.

I told Neil about the vespers service, as later that afternoon, we were whisked away in Yury’s limousine back to the airport to fly home. The limo driver’s name was Theo. He was a Romanian, and no relation to Leo. I mused, “Theo and Leo,” and I thought more about the notion of a secret agency, comprised also of angelic souls incarnated in human bodies to carry out individual mission assignments here on Earth. Were Theo, Leo, Reverend Rosencrans or even Grandpa members of this agency? Could I be a member of this agency? How about Neil? *What if* each of us were born to the role of an independent agent serving a greater collective? Perhaps we all belong to something so much bigger than our individual selves.

*Do you remember the white bag with the pile of magic notes, the SLTP CD dated 2011, and the safety pin threaded with a jingle bell? When I popped the CD into my computer, I found group photos, including several of Neil sitting with all the other members of the Scarecrow team. I also found some text files and opened one entitled “Portfolio,” where I read about putting together a service portfolio. A **service portfolio** is a compilation of documents that a student assembles to record of his volunteer work. It might include artifacts, photos, news articles, acknowledgments, and personal reflections that demonstrate commitment to community service, personal development, and leadership ability. These portfolios are an excellent conversation piece for college or job interviews. They bring an application or resumé to life for scholarship selection committees and other award programs. Portfolio pieces must, however, meet a set criteria for inclusion.*

“Sharing your time and talents for the benefit of others is an important part of everything SLTP stands for. 'Walking your talk' requires sensitivity, perception of need, determination, perseverance, and dedication. To qualify for recognition your Public Service activities must be performed without pay, compensation or school credit. You should provide a direct service, rather than focus on issues. When setting your goals, identify activities that benefit the community at large.” - Jim Fitzgerald, Founder, SLTP

I wondered if Neil had assembled a service portfolio. He never mentioned it. I do remember that one of his first meaningful volunteer activities was helping a needy family in the neighboring town of Warwick rebuild and refurbish a home. He also helped organize a beach clean-up, and he tutored peers in math and science.

Searching through Neil's bookshelf I found a black binder holding documents of recognition – athletic, academic, and leadership awards. Tucked in the front pocket was a local newspaper article dated April 5, 2007 – “Checkmate: EG grade-schoolers capture chess championship.” Neil and his three middle school team mates had won the first place trophy in the Rhode Island Scholastic State Championship.

*As I flipped through the pages of the binder, I also noticed there was a clear theme of personal development. It began with the documentation of participation in soccer. Team sports provide tremendous opportunities for personal growth, because they require players to practice valuable life skills as they undertake group challenges. Individuals learn about competition, confrontation, cooperation, and what it means to actually belong to a team. The following story, **Out of the Darkness**, tells of Neil's personal development through his pursuit of soccer.*

OUT OF THE DARKNESS

Neil had placed the documents in plastic sleeve protectors and arranged them chronologically. The first sleeve held an award acknowledging his Black Watch Premier Soccer Team as the 2008 Rhode Island State Champs, along with a team photo. The team was a tightly-knit group of boys who had grown up playing soccer together. Neil was a latecomer, having joined the team around age 9. He played on defense with two other boys, Forgie and Ryno. The three boys formed what came to be known as “The Wall,” which was legendary in its time. I recall that, during that 2008 season, only one ball slipped by the three of them, past the keeper, and into the goal. “The Wall” was nearly impenetrable.

Then this fairy tale memory was tarnished. We were attending the team's year end banquet, to celebrate its success. Some parents had put together an extensive slide show capturing the action and highlights of the year. As the slides flipped past, one by one, I recall seeing Neil's face in only two of the many photos. One of them was the classic team portrait and the other was a candid shot of him sitting together with teammates in the grass on the sidelines during a coaching talk. The only other photo of Neil showed him with his back to the camera, waiting for the ball to come back down the field. The slide show had lots of fabulous action shots of all the other players, yet not a single action shot of Neil.

When the slide show ended, I looked across the dimly lit banquet hall to where Neil was sitting with his teammates, and I could read the crushing disappointment on his face. I felt a pain in my own heart. The lack of inclusion was surely an

unintended oversight. I scanned the proud faces of the parents, seated around the tables. Truth be told, I always felt like an outsider among this group, and although Neil was very much a part of the team, he was not feeling it that evening.

When Neil moved on to 7th grade the following year, he made the decision to leave his premier soccer league team and join the town's Cole Middle School team. Most of the faces were familiar. He was chosen to play midfield and really enjoyed it. After-school practices were a ten-minute walk from home, instead of a 25-minute drive through the city, and the middle school's soccer coach was a special kind of person.

Neil's portfolio includes a letter from this coach, written to all the boys and presented to them at the end of the season. It began like this:

“Over the last 21 years of coaching, I can remember certain groups or teams that have been outstanding. Two state championship teams I had at Coventry, one great year at Tollgate... and your soccer team.”

Then he went on to acknowledge the skills, attributes and importance of *every* individual player. For Neil he wrote:

“Neil... Ninja [referring to the black padded protective head band Neil wore]... the 1st day of try-outs... we all were asking what the heck was on that kid's head?? Well it Works! Great skill and quickness, always using the chess mind to stay one step ahead...”

What distinguished Neil's approach to soccer is that he tended to scan the soccer field in the manner he would a chess board, using his head to assess all the player positions. Wearing a padded head guard, that wrapped around his head like a ninja head band, to prevent brain injury. He was always ready to use his head, literally, to direct the soccer ball strategically – away from an opponent, out of bounds, toward a team member or toward the goal. Neil had actually become accustomed to wearing padded head gear and shin pads at a younger age, when he engaged in taekwondo sparring matches.

After the Cole coach acknowledged each team mate, he concluded by sharing his own personal story, sage advice and gratitude:

“The coach... has been out of coaching for a couple of years. 3 young kids at home. But as most of you figured out during the year, I have Parkinson's disease, which is what really kept me from coaching. It was nice to be back... and you and your parents made that easy, although you might not know it. After coaching in high school, some might see middle school as a step down... I saw it as a chance to teach/coach, hopefully you all had a good year and learned something.

“You all are going to have 'curve balls' thrown at you, or things you're not ready for. Maybe you don't make the high school team, do poorly in class, or get turned down by Roxy... whatever the case may be,

stay positive, work hard; never quit... and good things will happen. Keep playing...

“Parents....you have a great group of boys...they were a group of characters....that's for sure. Especially when around the girls soccer team....anyway...

Thanks for your help and support. The pasta parties were a big hit, and brought the team together nicely... they really were a TEAM. Some might say the coach helped, but as a coach, teacher and parent...I think we all know everything starts at the home...Thanks”

Neil did make the high school soccer team, however, he found the experience somewhat dispiriting. He would come home at the end of the day and tell us stories about how the older players gave him and other freshman players a hard time. Soccer was no better during sophomore year. Nevertheless, Neil stuck it out, while attending to his academic studies and leadership training. At the start of his junior year, Neil applied for a Leadership Trainer (LT) position for SLTP's 2013 summer session, and he was accepted.

One of his first assignments as an LT was to help plan and run the Fall 2012 Re-Energizer Weekend Conference. Every fall the SLTP staff members collaborated to write and perform a play, which promotes discussion and critical thinking about an important issue. I found the script in Neil's storage box. The 2012 play, titled **Run to the Darkness**, placed a spotlight on fear and was dedicated to Hope. The production was inspired by the lyrics of *Go Light Your World* by Chris Rice:

*“Carry your candle, run to the darkness
Seek out the hopeless, confused and torn
Hold out your candle for all to see it
Take your candle, and go light your world”*

The students developed nine scenes, and called them “windows.” During the performance, the actors scattered themselves throughout the audience and took turns performing. The first window looked into the lives of different characters and the fears they were facing. Fear was all they could see in the moment, and fear was robbing them of hope. Each subsequent window shed light on these various fears in more detail, so they could be shared with the audience. The technique allowed everyone to face the fears together, head on. The underlying message was that no one needs to face their fear alone. What affects one affects all. Ultimately, this play was about going into the dark places to help others find *leadership*.

I instantly recognized Neil's character in Window One. The monologue mirrored his personal experience as a freshman on the high school soccer team.

Ted: Hi, I'm Ted. *(pause until the audience adjusts to your location)* What's wrong with me? What am I so scared of? It seems kind of silly that the thing I was worried about all summer was the hazing that I knew awaited me as a freshman on the sports teams. It continues to make me nervous. It has been pretty nasty. But it is crazy, the other day at the Rally a couple of kids were hit by batteries that were thrown at them just because they were freshman. My teachers say that everyone goes through it. WHY? Everyone

tells me it is better than it used to be. They tell me that I need to wait until I get to basketball though. And now those stories scare me. Most of the soccer kids are not playing basketball. Those that are just laugh at me and say “just wait.”

The battery throwing incident had been reported on a local news site. I remember reading about it. Apparently, the annual Spirit Week pep rally was always a bit of a ruckus. This time, a student was hit by an airborne "D" battery that was lobbed by another student. Traditionally, the freshman class takes a lot of heat at this event. Freshmen are forewarned throughout the week before the rally. When they arrive, the upper classmen chant "Go back to Cole." After the batteries were thrown, school officials stopped the pep rally and said the Homecoming Dance would be canceled unless the perpetrators came forward.

In Window Two, Neil's character continues his storytelling and is joined by a second character, Ted's mom.

Mom: Hey honey, how was your day?

Ted: Eh, it was okay.

Mom: Only okay, why's that? Trouble at soccer again?

Ted: (*sad*) Yeah, don't worry about it though. It can't be fixed.

Mom: Well you know I hate seeing you like this honey. What was it this time? What did they do?

Ted: Nothing Mom, don't worry about it there is nothing you can do.

Mom: You know I'm worried about you, you haven't been the same lately. You've been more quiet and reserved.

Ted: *(Deep breath) (exasperated tone slowly getting faster and faster as the words flood out)* They're always picking on me Mom. Everything we do. It doesn't matter what we are doing, I feel like a target. Whenever we play possession drills with a few people in the middle and the rest on the outside, it's always me in the middle. When I finally get the ball because I'd worked my butt off for it they make some lame excuse and tell me to get back in the middle, or they pass the ball to me extra hard and blame me when I couldn't control it and the defender gets it. I tried questioning them once and they laughed at me and told me to shut up that I sucked at soccer. And they force me to lug both bags of balls to and from the equipment shed everyday before and after practice. It seems like they hate me but I don't know why. I never did anything to them. Yet it's like they are trying to squish me into the ground like a measly little ant. It just sucks!

Mom: Oh honey, that is horrible! *(angry tone)* No one can treat my son that way. I'm going to have a word with the principal about this. That is unacceptable. How can school be a safe and supportive environment with stuff like this going on?

Ted: *(scared)* No! Mom please don't! If you talk to the principal he'll call me down to the office and have me talk with the guys on the team with him in the office. I'll lose all

respect from everyone on the team. I won't even be able to walk down the hallway without people looking at me and laughing at me. I'll be the laughing stock of the school, everyone would hate me.

Mom: What do you expect me to do then, sit here and let you take this abuse? It kills me to see you look like this! Something has to be done. You come home looking more worn out everyday.

Ted: Yeah, I know, but I can't become the laughing stock of the school. That would be worse than anything. I am strong, Mom, I can handle it. I'm probably over thinking it anyway. Maybe I'm just a little tired and being too judgmental.

Mom: If you're sure. But don't let them pick on you like that. Stand up for yourself if you won't let me do it for you. Talk to your coach or something. He might be able to help you with this problem. You're sure you don't want me to talk to somebody for you. I'll make sure they never bother you again.

Ted: No, Mom, I can handle it myself. I'm in high school now I can handle my own problems. I'm just tired that's all. I'm going to lie down for a bit then I have to get to my homework.

Mom: Okay, hon, let me know if you need anything.
(leaves)

Ted: (says to self) Uhhhhh. What am I gonna do?

I knew this scene and how it would play out. I also knew why Neil made this contribution to the creation of Run to the Darkness. The youth conference provided students with a safe forum to share their dark moments and bring them out into the light of day. As a parent reading this script, I wonder how many people can relate to Neil's experience. What else do young people fear, besides being ridiculed or looking weak? The following windows explored the fears of asking for help, not being liked, not belonging, being alone, not being good enough, becoming unpopular, losing friends, being wrong, being hurt, and much more.

So, how did Neil handle his problem, and how did it work out? He decided to talk to his soccer coach privately about the hazing. Unfortunately, he came away from that conversation with the perception that the coach didn't care enough to do anything about it. In fact, it seemed to Neil as if the coach's response was to bench him, indefinitely.

Dean and I attended the soccer games hoping to see Neil get a chance to play. The home games were held on the turf of the high school's new football stadium. In front of the gate to the stadium is a life sized statue of a knight on a horse, representing the high school mascot, the Avenger. To the right of the entrance were new high rise bleachers, topped by a press box. We usually stood at the edge of the field, just inside the fence that separates the bleachers and spectators from the field.

Neil's opportunity to prove his ability finally came during the Fall of his junior year, and I will never forget that day. It was raining, and a couple players were injured. The coach sent Neil onto the field, and, at that very moment, the sun came out and a rainbow appeared in the sky beyond the far side of the

field. Neil would not have seen it, because his head was now in the game. For me, however, it was a telling sign. Neil played with all his heart and soul, and he played well. He showed what he was worth to the team. And, he played every game after that. His Avengers team would never be a championship team, like Black Watch, however, Neil *would* be doing what he loved best, playing.

It should be no surprise that Neil made a point of treating every team member as a valued member of the team. He was inclusive and treated everyone with respect. Rather than ridicule the freshmen, he did his best to be a caring role model. He had no fear of showing that he cared. Many people fear showing they care, because they are afraid of getting hurt. Not Neil. He had learned some truths about facing his fears and about caring. I found Neil's realization of this personal accomplishment written in one of his SLTP notebooks, "Coming out of the darkness as a shining light – making it through elementary school having dealt with my problems effectively."

On the bookshelf next to Neil's computer table is a treasured book, Walk in Their Shoes, college reading for a social entrepreneurship class. Neil wrote a Facebook post about the book on February 8, 2016, one month prior to his diagnosis:

"Recovering from three concussions while going through some other serious life traumas has made the past four months of my life some of the toughest I can remember. Each day has provided its own struggle, and some days, I have just plain felt like quitting. I'd say to my resigned self, 'That's it, let me just hibernate for the winter and wake up a new man in May. I'm done.' It is on these depressed days that I would pull out my bookmark from 'Walk in Their Shoes,' dive a couple pages deeper into Jim Ziolkowski's life story, and find myself moved, in many cases, to the point of tears. Every page is filled with so much heart, compassion, and inspiration that saying I was/am inspired is almost an understatement.

"As one of the most moving stories I have ever had the pleasure of hearing, 'Walk in Their Shoes' has given me more than just the motivation to keep plugging away at life. It's given me the inspiration and the aspiration to make more of it. In his awe-inspiring story, Jim takes you on a journey away from the comfortable recesses of your home, out into the streets of Harlem, and off through the wastelands of some of the poorest countries in the world on one of the most touching and meaningful journeys that life has to offer. From the most forsaken corners of Haiti to the deep recesses of Nepal, he has traveled forming bonds, building schools, and spreading light. His story represents a beacon of hope, in what often seems a dark and desolate landscape.

“For anyone out there having a rough time with life right now and looking for motivation to get back to making a difference in the world, I highly recommend picking up a copy of this book for yourself. Each and everyone of us has such an incredible potential to make a difference, all it takes is the right key to unlock this potential. So for all of you out there having a bad day or a rough time of it with life right now, I have short poem from the book to share.”

“Never Give up
No matter what is going on
Never give up
Develop the heart
Too much energy in your country
Is spent developing the mind
Instead of the heart
Develop the heart
Be compassionate
Not just to your friends
But to everyone
Be compassionate
Work for peace
In your heart and in the world
Work for peace
And I say again
Never give up.
No matter what is happening
No matter what is going on around you
Never give up’
~Dalai Lama”

NEVER GIVING UP

I sat on the bench and turned my gaze from the tennis courts to the plaque that was attached to the backrest. I ran my fingers across the lines of raised lettering.

**In Loving Memory of
NEIL EUGENE FACHON
1997 – 2017
EGHS TENNIS TEAM CLASS OF 2014
*“Never underestimate the power you
have to touch someone else's life.”***

Neil decided to join the tennis team during his junior year, and in so doing, he discovered a sport he would love more than soccer. The bench was installed and dedicated four months after Neil's death. I often think about the story Coach Marisa Salvadore shared at the bench ceremony. It goes like this:

“I had the distinct pleasure of coaching Neil on the Avenger High School team. He came on more as a soccer and chess star who had a little experience in tennis. Notwithstanding, he efficiently worked his way up the ladder and rose to the 4th singles position. His success came through sheer determination, willingness to work hard in practices and match play, and his consistently positive attitude.

“I loved that Neil not only worked on his game here at the courts, but he thrust himself into competition and

tournament play at Roger Williams Park. Often young or inexperienced players are afraid of match play and they find excuses to avoid it altogether or as to why they will not perform well. Not Neil, he was eager to improve, and you can see how much he enjoyed the challenge of tennis.

“One of his personal successes particularly stands out in my mind. He wore down South Kingstown opponent, Chris Gu, and we were able as a team to defeat SK 5-2 with a sweep in singles and a #2 doubles victory by Shevy Karbasi and Dylon Lo (over the Doubles team that ultimately went on to win the state tournament). It was a sweet day for EG as SK is always a vaunted opponent with a boatload of championship titles.

“But the sweetest part of the victory was in Neil’s match. It was only our third team match of the season, and Neil had just made the jump from #2 Doubles to #4 Singles, and this was his first official Singles match for the team. This could seem like a scary proposition or like a fantastic opportunity to challenge oneself. I just love the players, like Neil, who embrace the latter sentiment.

“Neil knew his opponent well from chess tournaments. When they saw they would be competing, both seemed excited to see how their wits and skills would match up on a tennis court. Not that I told Neil this, but the edge went to Chris, who had a lot more tennis experience,

and two years of singles on a championship team under his belt. Chris jumped out to a resounding lead. Neil was down 0-6, 1-5.

“I often tell my players a match isn't over until the last point is played. Often facing such a mountain though, I see players rush to just get the horrible, losing feeling over with; and they cave. They will attempt almost any low percentage shot to get off the court and be done with the incredible feeling of pressure.

“Not Neil, though. He began his relentless fight back. He showed a resounding stand of determination, defending several match points in different games of the 2nd set. He turned on his soccer skills and chased ball after ball and became a virtual wall.

“All of a sudden the pressure shifted to Chris. 'Come on already, what do I have to do to win this match?' I imagined he was thinking. Once that acknowledgment of respect for his opponent's willingness to fight and leave it all out on the court crept into Chris's head, the match was ripe for the taking. Neil turned the second set in his favor, and Chris didn't stand a chance. He just did not have the same fortitude as Neil. What could have seemed like a clean slate and anyone's match, was now clearly just Neil's. He ultimately defeated Chris, 0-6, 7-6 (8-6), 6-2. I don't know this to be true, but I got the impression after that come back, that Neil would never lose to Chris in Chess or Tennis again.

“As a coach, I could not have asked for a nicer player. You love some players for their sheer athleticism, some for their talent, some for their leadership and sensitivity to teammates, some for their consistent hard work, some for their helpfulness, and some for their ready smile. I sincerely can say, I loved Neil for All of the Above.

“Even though I am the coach, I learn a lot from the players. Without a doubt, I draw from my relationship with Neil and feel fortunate to carry him in my heart. My boys [her own two sons] know Neil, but many of the current players did not get that honor.

“I am thrilled to have a specific place where we, as a team, will come seek support for our weary legs and we will share stories of Neil and other inspirations. Here, we will come and hopefully spur our players to reach deep down inside and pull out their greatest potential, on and off the court.

“Neil would love nothing more than to see young teens face and embrace challenges and rise to the occasion with an open heart, a ready smile, and an open mind.”

Neil's teammate Shiv Patel also spoke at the dedication ceremony. Neil met Shiv in middle school, and they became closer friends in high school during science labs and tennis team practice. Shiv held the #1 singles slot for the tennis team. Although Shiv was a better player, the two boys loved practicing together. This helped Neil improve his game. Shiv shared a humorous memory of practicing with Neil, along with other memories and personal reflections.

“First and foremost, Neil was always there for me. No matter what it was, he was a friend that I could talk to about anything, whether it was as general as our philosophies on life or as specific as the chemical formula for Octanitrocubane, Neil and I always had healthy conversations that helped us learn more and more about each other and about ourselves.

“Particularly, when I think of Neil, one of the first memories that comes to mind was how eager we were to get onto the tennis court our senior year of high school. It was early March, and pounds of snow had just fallen on the ground. Neil, sharing my love for tennis and drive to improve, suggested that we shovel the courts free of snow and start practicing a week early. A little ambitious, yes, but to me, this idea sounded brilliant. So we went to the courts, shoveled for about an hour, and at that point had only cleared about a tenth of one tennis court. In other words, it slowly dawned upon us that we would not be able to shovel all the snow off the courts even if we had a year, let alone a week. So what'd we do, we

started brainstorming more options, maybe we could get snow blowers, or bigger shovels, or a snow plow to come onto the court. Of course, none of this ever happened, but I tell you that story to demonstrate Neil's creativity and belief that there was always a solution, we just had to look hard enough to find it. I think this was in part what attracted me to Neil's personality, a very rare trait, which was his infectious confidence and belief in not only himself, but also in all those around him that we are capable of doing anything we put our minds to...

“Although we couldn't get all the snow off the courts that day, we had conversations that quickly turned into our hopes for the future. We started talking about how we were going to improve, our specific plans to get better, and our hopes of winning a championship. Knowing Neil possessed that crazy competitive fire that I did, he was willing to put in the extra hours with me, which meant we started practicing together even after our set practices.

“Our shared passion for tennis allowed us to improve, but more importantly, it made our bond stronger. Naturally, we no longer just spoke of tennis, although we still did a lot of that, we talked about personal matters like how we viewed the world, heartbreaks from the past and how to overcome them, and our hopes and dreams for the future. No matter what we talked about though, Neil's aura always radiated optimism and inspired me to want to improve myself

due to his kindness, dedication, commitment, and overall sincerity in all that he strove for in not only his academic and athletic endeavors, but also in every single act and thought he had.

“In each interaction with Neil, I could sense his desire to spread this kindness. He'd always start all of our conversations with "what's goin on in the world of Shiv?" Which always let me know he truly cared about my perspective and what I was going through.

“In school and in class, Neil was a pleasure just to be around. When we crossed paths in the hallway, he'd always greet me with his signature salute along with a smile from ear to ear. I can't explain it, but that unique greeting for some reason always made me smile and brightened my day regardless of what we were feeling or what was going on. He had that ability to just make you laugh with his laugh and his optimism for all that we were doing.

“In class, he was always super curious and would never stop until he understood a concept. Having been in AP chemistry and AP physics with him, I watched as he asked questions and spoke to Mrs. Schnacky [chemistry teacher] and Mr. Lenox [physics teacher] to understand complex concepts incomprehensible to me. I was always impressed by Neil's intellectual curiosity and his ability to learn so quickly. It was almost like every time he was trying to solve a problem, he entered this laser focus zone,

where he relentlessly brainstormed and tinkered with things until he found the solution.

“I remember this one time we worked on a speaker project together, and the material we were using wasn't working. He consulted Mr. Lenox, discussed potential solutions, and then tried out those solutions over the next two hours until we maximized our speaker's potential. The most important task to him was always the task at hand.

“In that example and many others, Neil's ability to focus at any moment in time on completing a task was second to none. But throughout his life and condition, I believe his ability to focus has strengthened over time and is what has allowed Neil to be Neil in general. After a conversation we had in his backyard on a beautiful day last summer, I wrote down a quote from Neil which reads 'Meditation conserves energy and allows you to channel it exactly where you want it to go.' (Him being the Zen master of course, I remember Neil making the meditation symbol with his left hand a few months ago) Neil taught me and all those around him that channeling this energy towards love, compassion, and laughter always makes the world a better place, and for that I am forever grateful.

“Moving forward, Neil's spirit will forever live on in my soul and all the souls he has touched. Recently, I noticed this first hand in training for and running my first marathon, when Neil's spirit pushed me through

any moments of pain or doubt. Whenever I felt like quitting, I remember how hard Neil fought for a year, how he beat the odds, and how he lived the motto 'Nothing's impossible' to do what had never been done before. What will always resonate with me as his spirit lives on is to never be afraid to care, to believe that anything's possible, and to channel as much energy as we can towards making this world a better place.”

Another tennis practice partner, Heather Shen, who had helped the Women's tennis team clinch the Division I state championship, wrote the following memory:

“I met Neil about six years ago, during the unfortunate age of inch-thick glasses and braces. In a small town like East Greenwich, RI, being in multiple classes with the same people each year isn’t uncommon, and somewhere between chemical reactions and starting a robotics club together, Neil and I became friends. For that, I am grateful.

“Whether it was his warm laugh when he joked during chemistry class, 'Think like a proton. Always positive.’ or his reassuring gaze when I got frustrated during robotics, Neil taught me to approach each challenge with positivity and grace.

“During the hours we spent tinkering with robotics — between the precipice of 'wasn’t there another screw over here?' and 'where should this wire go?’ — Neil’s consistent positivity kept our frustrations at bay. On our fifth or sixth or seventh attempt to simply make our robot

move, I was ready to give up. I was tired and angry and questioning why we even started this endeavor. But Neil persisted. He let me rant, and then said, "Let's try again." He knew when words were not needed nor wanted, but he also had that rare ability to know just what to say to push people to challenge themselves.

"Yet perhaps the most important lesson I learned from Neil is to approach each person with an open heart. After we both graduated from high school, we sporadically messaged each other for brief updates. Looking at old messages, I found one which spoke to Neil's faith in and love for people: we were talking about our summer traveling experiences, and he said, 'I'd start talking to some Italians in broken Italian and they'd end up buying me drinks. And that's just how they are there. They aren't rich, but they are generous and caring.'

"Neil saw the best in people, and brought out the best in others. Like so many of the other people Neil touched, I will carry his philosophy of compassion and empathy with me as I face new challenges, experience new cultures, and meet new people. For showing me what laughing at frustration is like and for opening your heart to me and everyone around you, thank you, Neil."

Ben Martino, another high school tennis teammate wrote:

"What was remarkable about Neil was that you could never tell when he had a bad day. He would never radiate negative energy because he knew that it could affect his tennis team. He never seemed to give in either. He would be at his teammate's side for as long as they needed his

support. Neil certainly helped with team building and making us all think about the game being a team effort, even though the match was into singles or doubles.

“Another important aspect of the game that Neil brought to life was sportsmanship. Even when the other team would be making questionable calls on their side of the court, that would never be an excuse to act the same way for our side. Wins or losses are not what makes the game enjoyable, but being a good spirit is, and Neil was an amazing partner to have.

“This selflessness can also be seen in his work at SLTP. Neil would always say “You need to try SLTP,” and eventually I gave in. The program helped me grow socially, and Neil was always the friendly face I could rely upon. He loved to tell the story of The Jester Has Lost His Jingle, and this helped everyone open up more. To be a leader at SLTP requires a special personality; not everyone is fit for the task. They are truly difference makers, and genuinely want to see the world become a better place.”

When moving from a small high school to a large university, qualifying for a place on a competitive team becomes tougher. Neil tried out repeatedly for the Northeastern tennis team, failed, and kept coming back to try again. He finally made it, however, at the same time he was beginning to have difficulty with his vision and coordination, and he had to take leave of the club. After learning he had cancer, he received a number of uplifting letters from tennis teammates, including this one:

“I'm really sorry I couldn't get a chance to see you before I left for my clinicals. I'm really writing you this letter to tell you Thank You. In my 5 years at Northeastern and being on this tennis team, I have never met someone quite like you. Even though you were competing and training with us for a short time, I truly learned so much from you. Looking back on all the times you tried out, you never gave up, you were never discouraged. You did just the opposite. You worked hard and ended up making this team in a unique way. You were called up mid Fall 2015 semester not only because you could play, but because of the type of person you are. From day 1 getting to know you, you have only brought positivity, hard work, dedication, and a great understanding of a team mentality. When people counted you out, you always came back ready to go. As you know, we have great talented players on our team, but not everyone had the amount of heart and mindset that you brought to us EVERY. SINGLE. DAY. Your attitude is amazingly contagious, and it is something I think about constantly and strive to achieve in everything I do. It was an absolute pleasure to be your President and Captain this year. Thank you Neil for being that guy who could follow and lead by example. Everyone might not have gotten to know you like I have, but like I always told you, 'Once you're with us, you're always with us. You always have a home with NEU TENNIS.' Keep fighting bud, like you always do. Here's a little swag for you, Enjoy!

We're all rooting for you.
Anil Nandkumur
and the entire Northeastern University Tennis Team”

Tennis mom, Audrey Caron, had launched a GoFundMe campaign to raise funds for the memorial bench, and, in less than three days, she raised over \$3,000 for the project. Her son Marcus was one of Neil's NEU Tennis team mates.

Meanwhile, Northeastern hosts a Midnight Madness Tennis Tournament every year, inviting teams from all over come New England to participate and help fund raise. Half the funds are sent to The Jester and Pharley Phund, an organization Neil had served with such great passion.



The Jester & Pharley Phund's mission centers around a special children's book about a Jester. I pulled the book from Neil's book shelf, sat on the floor and opened it to the title page – The Jester Has Lost His Jingle by David Saltzman. I read the inscription written to the left of the title page:

To Neil,

May The Jester & Pharley always bring a smile to your face and laughter to your heart. Never lose your jingle!

Love,

The Jester's Mom

Barbara Saltzman's

3/21/16

The book arrived at our house three weeks after Neil received his terminal diagnosis. The package included a Jester doll, with jingles attached to the Jester's velvety red cap and to the tips of his velvety red shoes. Although Neil, then 19, was no longer a child, no gift could have meant more to him. He knew the story well, having listened to it many times and having read it many times during his years of involvement with the Student Leadership Training Program (SLTP). The book continues to be a constant reminder that even in the darkest of times, there are reasons to laugh, smile, and stay hopeful.

SLTP's five-day leadership camp was devoted to building character. Those efforts culminated with a service project, which always centered around David Saltzman's magical

children's book. David, an English and art major at Yale University, was diagnosed with cancer during his senior year. For the next year-and-a-half, he kept a journal of his thoughts and drawings while completing "The Jester Lost His Jingle" and other stories. David died on March 2, 1990, 11 days before his 23rd birthday. Five years later, his parents published The Jester Has Lost His Jingle as a book. They printed 10,000 copies of the first edition to provide to hospitals to give to children. Over the past 25 years, the Phund has donated over 200,000 Jester books and dolls to children in over 350 hospitals. The following story, **The Difference Maker**, shares a little bit of the Jester's magic and a lot of hope.

THE DIFFERENCE MAKER

It was mid-February, which meant we were approaching the two-year anniversary of our son's death. I was sitting at my computer, honoring his memory by writing about a fund raising blog, titled "Be a Difference Maker." I wrote about the Student Leadership Training Program (SLTP) service work our son, Neil, had undertaken during his high school years for the Jester & Pharley Phund. The Phund is a non-profit dedicated to bringing the joy of laughter and the love of learning by donating copies of David Saltzman's uplifting storybook, The Jester Has Lost His Jingle, to children who are ill or have special needs. I typed:

"Regarding the service project, SLTP founder Jim Fitzgerald explains, 'It is a defining time for our kids, and we celebrate their feelings by sharing David's wonderful story about choices and the meaning of love. The group explores the concept of service and how to make it more meaningful and less of a chore.' At the end of the difference maker workshop, each student receives a large, decorative safety pin with a jingle bell to wear at future SLTP events. 'We tell them,' says Fitzgerald, 'When you hear the bell jingle, you need to remember: It's up to YOU to make a difference. It's up to YOU to care.'"

There is a well-known parable about difference making. One day, an old man was walking along a beach that was littered with thousands of starfish that had been washed ashore by the high tide. As he walked he came upon a young boy who was eagerly throwing the starfish back into the ocean, one by one. Puzzled, the man looked at the boy and asked what he

was doing. Without looking up from his task, the boy simply replied, “I’m saving these starfish, Sir”. The old man chuckled aloud, “Son, there are thousands of starfish and only one of you. What difference can you make?” The boy picked up a starfish, gently tossed it into the water and turning to the man, said, “I made a difference to that one!”

In the midst of his illness, Neil received an envelope filled with 56 paper stars. A different name was written on each star. There was also a letter written by an SLTP co-leader:

“Dear Neil,

“I've known about your diagnosis for a little while now, but I didn't know what I could say or do that would make any difference. Everything I could say felt like it wasn't nearly enough. So I started thinking about what I most want you to know, and I finally realized that I want to remind you what a difference you've made, and continue to make. These stars represent the 56 campers from session 2 of 2014, the year that we were teaching partners. You made a difference for these starfish. And I'm so honored that I got to be a part of that.

“I've always enjoyed getting to work with and spend time with you. You are one of the most intelligent people I know, and you're always so excited to start wrapping your head around a new challenge. You care about everything so hard. One of my favorite quotes is from Henry James, and it says, 'Try to be one of those on whom nothing is lost.' You are one of those on whom nothing is lost. You pay attention to everything, and you give attention and a listening ear to anyone who needs it. Watching you teach and interact with people during session 2, and throughout the time we got to spend together on staff, made me a better teacher, a better leader, and a better person.

I'm very lucky to know you, and I know everyone who gets to spend any amount of time with you feels the same way.

"I'm hoping having these little starfish to look at will help on the hard days. I hope they remind you of how many people you've touched. You are strong. If you ever need someone to talk to and remind you of that, I'm always here.

"Sending so many good thoughts and prayers your way.
Hoping you're having a good day.

"777,
Marty Petronio"

There is a basket full of letters in Neil's room. As his illness progressed, friends would write to touch base, send cheer, and offer encouragement. Being familiar with David's story, Neil's SLTP friends knew how much these letters would mean. Back to my blog typing:

"Many SLTP students returned to their high schools and implemented The Jester & Pharley Phund's 'Reading To Give' program in their local elementary schools. Neil volunteered to lead the program in East Greenwich. He teamed up with other SLTP students, planned meetings, coordinated the paperwork and helped present dramatic readings of the book to elementary classrooms. Then he enrolled the younger students in read-a-thons to raise money for giving Jester books and dolls to pediatric cancer patients at nearby hospitals. He also helped thread beaded jingle bells to give to the younger students as a reminder of the Jester and his joyful spirit.

"Four years later, when Neil was hospitalized for brain surgery and again for pneumonia, I wore a jingle pin he had

made. I wore it everyday to the hospital, because it reminded me of one unforgettable character in The Jester Has Lost His Jingle, a little girl lying in a hospital bed with her head wrapped in a bandage. The Jester visits her room, talks with her and cheers her up. It is the most precious moment of the story. It is where the Jester discovers he still has his jingle – his ability to bring joy to others. And so, I wore the pin as a reminder to keep my own spirits up, because I was one of Neil's jesters. During those dark December and January days, and I needed to stay positive, no matter the difficulties.

“Many people are unaware that when a child has a serious illness, his or her life can become depressingly isolated. Some children are so sick they are unable to go to school and be with their friends. It is easy for the kids at school to forget about the friend who is not present. While siblings, parents and caregivers do their best to tend to the well-being of a pediatric cancer patient, that patient sorely misses the company of friends. Friends are special! Friends are the jesters of life!

“Since Neil’s passing on February 19, 2017 from DIPG brain cancer, \$20,401 in cash and in-kind contributions have been given in Neil’s memory to The Jester & Pharley Phund to help bring joy and laughter to hospitalized children. These kind gifts have resulted in the donation of 577 Jester books and 448 Jester dolls to hospitals, as well as the donation of a Smile Cart to Camp Sunshine.

“The Jester Has Lost His Jingle is Dream Visions 7 Radio’s February Kids Book-of-the-Month. For every \$10 donation in Neil’s memory, The Phund will be honored to donate a copy of 'The Jester Has Lost His Jingle.' The donor and Neil will be acknowledged in a bookplate...”

The day after I published the blog was a mild winter day, pleasant enough to visit Rome Point Beach, a stony beach on

the west side of the West Bay, where we sometimes went walking as a whole family. We remembered the time Neil was given an assignment to find a stone that spoke to him, save it to share with his SLTP peers, and explain why he picked that particular stone. He had found his stone on Rome Point Beach.

When Dean and I reached the beach, the tide was low. We noticed lots of toenail shells standing upright, poking out of the sand, shiny and translucent in the morning sunlight. I had never seen toenail shells look so orderly nor so beautiful. I was used to finding toenail shells lying flat in the sand, and looking more like, well, toenails.

These paper-thin delicately hinged shells belong to a small mollusk. The upper half of the shell is convex and movable, while the lower half stays fixed in place. Byssal threads, secreted by a gland near the mollusk's foot, pass through a hole in the bottom of the shell and anchor the mollusk to a rock or other hard substrate. Mollusks include scallops, clams, oysters and mussels. They are all filter feeders, taking in water and filtering plankton and other food through ciliated gills – gills with hairlike projections.

It is difficult to pick up live toenail shell mollusks and toss them back into the sea. When I delicately plucked the shell out of the sand, it appeared that the mollusk had slipped away through the hole in the bottom, leaving me holding an empty pair of coin-shaped shells, still attached at the hinge. Measuring 1-2 inches, the yellow-gold or silvery-colored toenail shells are one of the ocean's many treasures. I tucked a few in my pocket. We had been collecting unhinged and abandoned toenail shells for years, and I often called the shell by a second more fanciful name, however, I could not remember it in that moment, which bothered me. I asked

Dean, “What is that other name?” He had no idea.

As we continued walking along the shore, I spied a ball. It was metallic-colored and perforated with two rows of oblong holes, like a big jingle bell. I picked it up, only to discover it was a plastic wiffle ball that had acquired a tarnished gold appearance from a thin coating of algae. Suddenly I realized the ball was the answer my question: *What is that other name?* It was as if I had been playing a game of charades with some unseen team mate. Sounds like... Jingle Bell... of course... Jingle Shell!

Jingle shells are a favorite find for beachcombers, often used to make necklaces or wind chimes. This name was inspired by the chiming sound several shells make when they are strung together. The jingle sound is also heard when waves beat down upon beaches strewn with these shells. It sounds similar a handful of loose coins shaking around in a pocket or a money pouch.

Jingle Shells, Jingle Bells... The jingle shells scattered around the beach made me think of the jingle bells we had strewn around the church reception hall after Neil’s memorial service. The bells were a token of remembrance for guests to take home. Each golden bell was tied with a gold ribbon, the symbol of childhood cancer, and twists of sparkly pipe cleaners, in memory of a holiday tradition created by Neil.

One Christmas, when he was five years old and no one was looking, Neil opened a bag of sparkly pipe cleaners and twisted them into odd shapes. Then he placed them carefully on window sills, shelves and tables around our home. When we discovered what Neil had done and asked him about it, he replied, “I’m decorating the house with ‘spirits.’” The setting

out of these spirits became his annual tradition, and we continue to do this every Christmas in his memory.

I held the tarnished wiffle ball in my hand as we continued to walk the beach. The *only* other piece of plastic trash I found that day was a red cap. A red bottle cap with a crown insignia on it. I thought about how the Jester wears a red cap, and about how for four years of SLTP summer camp sessions, Neil helped decorate hats to give to hospitalized children.

Later on the same day, as I was taking another walk around our neighborhood block, I found what appeared to be a fabric coin pouch, useful for the safekeeping of a coin-sized red cap and a few jingle shells. Was it possible that all these serendipitous discoveries could have been a death anniversary gift and message from our son?

Thank you, Mom, keep up the good work. I'm still here, and all is well.

As we were waiting with Neil to meet with the oncologist, an intern showed us the MRI brain scans taken the day before. The images were frightening. Then the oncologist joined us and stated, with 99 percent certainty, that Neil had DIPG – diffuse intrinsic pontine glioma – a tumor originating in the pons. The largest part of the brain stem, the pons contains clusters of neurons that relay signals related to sleep, respiration, swallowing, bladder control, hearing, equilibrium, taste, eye movement, facial expressions, facial sensation and posture. These neural pathways were being impinged by an increase of swelling diffused throughout the surrounding glial tissue. This explained why Neil was having problems with vision, swallowing, speech and balance.

*Due to its location and diffused nature, DIPG is inoperable. It is also aggressive, with a mean survival time of nine months from diagnosis. Neil's diagnosis had already been delayed by five months (When the first symptoms appeared, the attending neurologist's opinion was that an MRI was unnecessary). The oncologist told him there was no cure and delivered a prognosis of three months. Only three months to live. Neil put his head down in his hands and said, "I'm f****d!" The doctor went on to suggest a course of thirty days of radiation therapy, which might provide an additional three months. It all seemed unreal, like a bad dream.*

That was Friday, March 4, 2016. Neil's world and ours was turned completely upside down. Everything in our lives changed. Neil, who had developed a reputation as a caretaker, was now the one who needed others to take care of him. Refusing to relinquish his own caretaker role, however, Neil deflected the concern of others by asking them questions about their own lives. The fact was, that even though he had

*terminal cancer, he was still able to help others, by sitting and listening. His brand of care taking required little physical effort. The following story, **Sugar Grams**, is about the power of listening as a form of care taking.*

SUGAR GRAMS

I begin every day by stretching out on a yoga mat in Neil's bedroom. As I finished my stretching this morning and turned to leave the room, I heard something fall. I walked over to the open storage bin of SLTP material. A *sugar cube* had tumbled out of the bin. What do I mean by a *sugar cube*? It is a Styrofoam sandwich take-out box with a slit cut into the top for the insertion of sugar grams.

Neil had served on staff as a Leadership Trainer during his last two years of high school. His commitment as an SLTP staff member included attending monthly training meetings, co-organizing the Fall Reenergizer, and going to the Annual Leadership Conference every Spring. At the conference, staffers praised one another by writing *sugar grams*. These tiny notes were personal and specific, acknowledging effort and progress. The point of writing sugar grams was to catch each and every person doing something right. Sugar grams are handwritten on little slips of pink paper, and collected in sugar cubes.

I sat down on the floor, opened the *sugar cube* and began to read the notes:

Neil, I really liked your mirrorlogue about fitting into the whole and being a piece of that. It was similar to my log. I especially liked your point about helping people not feel helpless. It fits so well with the stories you shared this fall about

your soccer team.

~ Mina

I quickly surmised that this sugar cube was created in the Spring of 2013; it seemed to have fallen deliberately into the semi-chronological sequence of my story writing. How perfect!

Being unfamiliar with the word *mirrorlogue*, I guessed it was a kind of reflective monologue. I continued to read more little pink notes:

I loved your mirrorlogue about being an individual who's part of a greater whole because you truly are an individual, always standing by your beliefs and standards and staying true to yourself, and I really respect that.

~ Mary

You're a great roommate and seemed like such a caretaker of those around you. I liked when you called yourself an individual and said you were part of an awesome SLTP community.

~ Graysen

Many of the staffers were moved by Neil's presentation. I'm currently reading a book, The Field by Lynne McTaggart, and am thinking how much Neil would enjoy it. On page 226, I read these words:

“We were not isolated beings living our desperate lives on a lonely planet in an indifferent universe. We never were alone. We were always part of a larger whole. We were and always have been at the center of things. Things did not fall apart. The Center did hold and it was we who are doing the holding.”

How perfect! The idea here is that each of us is becoming one with All or one in Spirit. Back to the *sugar grams*:

I loved that your mirrorlogue was about care taking because I watched you care take, share a smile or a hug with so many staffers when they needed it this weekend.

~ Caitlin

Thank you for checking up on me today when I was so tired. You are such a wonderful caretaker.

~ Liz

I'm so proud of you in so many ways. You care, and that is hard for guys, but you are okay with it. Never let anyone tell you that it's bad.

~ Chris

I like the caring personal theme because it fits you

so well. I see you listening and taking in everything everyone is saying and truly caring about the fellow staffers. You are definitely someone who can teach the camp that.

~ Gregorro

Thanks for sharing your liking of listening and caring! They're both so important to what we do here.

~ Iman

I love how self aware you are – it is not easy to share opening that you are shy and prefer to listen. The result of this is that everything you say is intentional and thoughtful. Thank you for that.

~ Bronson

I enjoy your willingness to share your opinions and to really listen to the opinions of others. You are sincere and thoughtful and really want to get to know those around you.

~ Gail

A couple years later, when Neil needed support during his darkest hours, many friends called by phone or stopped by to visit. I will never forget the day three SLTP girl friends came to see Neil at the Hope Hospice Center. It was around Valentine's Day of 2017. They brought him the gift of a black canvas, painted in bold white lettering, with words from the song Run to the Darkness:

We are a
● FAMILY ●
whose hearts are
BLAZING.
7, SLTP ♥

A large safety pin had been threaded through the canvas in the lower right corner, attaching a jingle bell and a button shaped in an open hand.

We left Neil alone with his three friends, who had come to entertain him with their stories. Immobile in his hospital bed, Neil was breathing through a trach tube. He could no longer speak, smile nor laugh, yet he could listen and be fully present with the moment. He had a special way of smiling, through his eyes, releasing fragments of light from the depth of his soul.

These special visits at the hospice center brought to mind a thought Neil had shared with me when he could still talk. He told me he was not afraid of dying; he was afraid of having to say good bye to friends. He was not afraid of how the good bye would hurt him. Rather, he feared how much it would hurt those he was leaving behind. As I stood outside in the hallway, an easy laughter flowed out the door. I was eternally grateful for these friends, who had come to ease his fear.

SLTP's 2017 Annual Leadership Conference was scheduled the same weekend that we had scheduled Neil's memorial service. Friends from the staff were unable to attend the Life Celebration, however, they set aside their own time for remembrance – by writing sugar grams.

The Friday following the service, Neil's math teacher and SLTP co-leader, Chris Boie, asked me to drop by the high school to pick up a couple of sugar cubes. There was a sugar cube for our family and a sugar cube for Neil. I brought them home and sat down immediately to read the messages deposited inside Neil's box:

Thank you for all the shared laughter and tears, you will always have a piece of my heart.

~ Samantha

I hear you when our group laughs. I see your smile in the faces of our staff. You have had such an impact on our program and the world. We will carry you with us always.

~ Brenna

It was an absolute honor and pleasure to serve on staff with you. Your enthusiasm and passion for the program could be felt by everyone. You're the definition of and one of my role models for being

a gentleman. You made and are still making a difference.

~ Doug

I'm so sad that we won't have the chance to staff at SLTP together. But your friendliness, warmth and love is something I think about all the time now that I am working with the program. I want to be as inclusive as you.

~ Steph

Thank you for your giving to SLTP and your spirit to help others. I see how you left other staffers so touched and I would want to be remembered like you man. Thank you. I will live life up every day!

~ Jake

There were many more kind notes, and after reading all of them, I went outside for a walk, under a blue sky streaked with wispy clouds, the kind that look like feather pens or angel wings. There was one cloud, however, that was clearly different – shaped like a puffy round doughnut with a hole in the middle. It was the brilliant white color of powdered sugar. As I acknowledged the cloud, it began to dissolve and within ten seconds magically disappeared. A sugar gram from heaven! Sweet!

After the oncologist delivered the devastating news, we took Neil back to his apartment at the university in downtown Boston. We were all in shock and disbelief. All we could think to do was cook up a healthy dinner with the contents of a CSA box of farm fresh food Neil had sitting on his kitchen table. Our daughter, Evie, who was a junior at the same university joined us. After our meal, a couple of Neil's friends showed up to hang out with him, and he sent us home. We left, reluctantly, driving through the darkest of nights back to Rhode Island.

At 3am, our phone rang. It was Neil, and he was having trouble breathing. We told him to call 911 and promised to meet him at the hospital. We raced back up to Boston on a highway so dark and empty that it felt surreal. Within the hour, Evie, Dean and I arrived in the emergency area. When we arrived Neil was breathing somewhat easier. Apparently, he had experienced a panic attack. We sat with him in a private ER room and waited for a doctor to examine him. We sought to combat the fear, by diverting Neil's attention and ours away from the dire prognosis.

Evie had brought along a book of comics, Zen Pencils: Cartoon Quotes from Inspirational Folks by Gavin Aung Than. At the top of one page was the quote "Never Give Up - Calvin Coolidge." Beneath the words was the first frame of a cartoon sequence depicting a boy flying forth to attack a fearsome dragon. The boy wore a cape and was armed with a wooden shield and a sword. Three defeated characters were lying beneath the dragon's feet: a knight, a wizard, and a monk, and the sequence played out from there.

Frame 2: The dragon struck the boy back with a blast of its fiery breath.

Frame 3: The boy landed flat on his back and his wooden shield lay beside him in flames.

Frame 4: The boy sat up: "Nothing in the world can take the place of persistence."

Five frames later the boy was climbing up the back of the dragon to drive his sword into the top of the dragon's head. In the last frame, the boy stood successfully atop the dragon, beneath the quote, "Resistance and determination alone are omnipotent. - Calvin Collidge."

A switch flipped on inside all of us as we sat together in the emergency room. We were going to fight this. With his chess brain, his AP science background, and a strong reputation as an impossible-situation-problem-solver, Neil was determined to find a better solution than radiation, which was neither a solution nor a cure. There had to be other options to battle the monster in his head, and this became his primary challenge.

*Together we set out upon an alternative and experimental path. We stopped by Neil's apartment to pack up some things, brought him home, and began doing a lot of intense reading and research to figure out what to do next. There is a single unillustrated line in the storybook The Jester Has Lost His Jingle that says: "They searched in every corner, under rocks and up in trees." That was our situation. The next story, **Leaving No Stone Unturned**, is about searching for hope.*

LEAVING NO STONE UNTURNED

Aware of my keen interest in natural medicine, Neil's 2015 Christmas gift to me was *The Sacred Science*, a video documentary about the ancient healing practices of the Amazon rain forest's shamans, whose knowledge of indigenous plants and rituals is now threatened by deforestation, modernization and ecotourism. The practices of these healers have been time-tested for centuries, yet they are little-known to the outside world. The documentary follows the cases of eight people from the developed world, as they embark on a one-month healing journey in the heart of the jungle. Several of the people sought treatment for cancer, and, ultimately, five of the patients return with measurable improvements and exceeded expectations.

On March 9, 2016, Neil emailed a query to the Sacred Science Team:

“My name is Neil Fachon. I am a sophomore industrial engineering student at Northeastern University. Let me first just say I love what you guys are doing and keep it up! There is so much knowledge out there, especially in the Amazon, that we have yet to tap into. Personally, I have always wanted to go to the Amazon to see these wonders first hand; however, I find myself in a bit of a pickle right now. I was just diagnosed with DIPG, a rare form of brain cancer that mainstream medicine has yet to successfully cure. My family and I, failing to accept the verdict, are reaching our webs to gather as

much information on alternative cancer treatments as possible. Naturally, you guys were some of the first people that I thought of. I got my parents the Sacred Science CD and cookbook for this past Christmas; however, they aren't sure where to find any of these ingredients. I thought I would reach out and ask you for your top few cancer fighting recipes and where we might be able to get these ingredients. Any help you can provide is greatly appreciated.

Cheers,

Neil”

He received an immediate reply from Deb via support@thesacredscience.zendesk.com. Deb started with a list of websites that sold ingredients and suggested beginning at a local health food store. She listed a number of other resources, as well as information about the shamanic healing center.

“The healing retreat center featured in the film is called *Paititi Institute*, which hosts extensive seminars in permaculture, sustainable living, traditional Amazon healing, and many other disciplines. Here is a link to their website:
www.paititi-institute.org

“You can contact them directly at info@paititi-institute.org for further inquiries about location, pricing, scheduling, or any other questions you might have. PLEASE NOTE that if you want to experience the healing process there, they have a prerequisite minimum 3 month

long Distance Healing program for anyone interested in attending the physical location – here is the link with the application to fill out.”

Unfortunately, we did not have three months to leave to such chance. While Dean got busy doing online research, I got busy reading a pile of books about alternative cancer treatments. These books were given to us by a dear friend, who happened to be a doctor of functional medicine. We plunged into a unconventional world of medicine that combined applied biochemistry with natural medicine. We made an appointment with another dear friend, Mary Blue, the owner of Farmacy Herbs in nearby Providence. The purpose of consulting with Mary was to identify an immune boosting herbal protocol that might help Neil buy some time.

We sat with Mary in her cozy shop, surrounded by jars of dried herbs, bottles of tinctures and shelves of natural medicine books. As we sipped tea, Mary asked Neil many questions about his illness and his body. She talked about which common herbs could boost immune, nervous and endocrine system functioning. She explained about how different herbs could support health in the liver, blood and brain. Then we watched as she opened a large plastic bag and began measuring and adding scoops from jars of dried dandelion leaf, red clover, nettle, tulsi, lemon balm and other herbs. She closed the bag and gave it a good shake, as she explained the steeping process and the daily frequency for ingesting the infusion.

Then Mary concocted a tincture derived from extractions of ashwaganda, St.Johns wort, poke root and other herbs. The tincture would support the adrenals, lymphatic system, and

other functions. Adrenal glands, located on top of the kidneys, produce hormones that help regulate the body's response to stress. A well-functioning lymphatic system is critical for fighting infections and assists in destroying old or abnormal cells, such as cancer cells. Together, we decided to label the bitter tincture *Warrior Juice*, and over the following months Neil stoically ingested one tablespoon three times daily.

In addition, Mary suggested Curcumin capsules. Curcumin, a spice derived from the rhizome of turmeric, is one of the most effective supplements for preventing and treating a number of diseases. In the case of brain cancer, Curcumin can travel through the bloodstream and through the blood brain barrier, where it turns on the signal in “sleeping genes,” which tell cancerous cells to die. Curcumin also promotes *neurogenesis*, the formation of new nerve cells.

Finally, Mary then referred us to Dr. Jody Noe, a naturopathic oncologist in Connecticut. *Naturopathic Oncology* is a medical field that combines modern science with natural medicine. Naturopathic oncologists work with conventional oncologists in an integrative model of cancer co-treatment. They are versed in the use of botanical medicine, homeopathy, diet, nutrition, and nutraceutical supplements.

Dean, Neil and I met with Dr. Noe, who recommended brain support supplements, which can travel through the blood brain barrier. She prescribed Omega fish oils, Alpha Lipoic Acid, Phosphatidylserine and a mushroom blend. She explained the purpose of each supplement in supporting different aspects of whole body and brain health.

Dr. Noe taught us about methylation, a biological process I wish was taught in high school biology class. She explained the importance of methylation to gene expression,

detoxification and the management of a body's biochemical pathways. Impaired methylation is a factor in causing cancer and other chronic diseases. To improve methylation, Dr. Noe prescribed Methyl Protect, a specially-formulated vitamin B complex.

At the same time, Dr. Noe told us no amount of pills could replace a healthy whole foods diet. She presented us with pages about bone broth, proteins, macronutrients, and meal plans. Nutrition and gut health are critical pieces of the puzzle that have been missing in conventional oncology. Traditional oncologists are schooled in radiation, chemotherapy, and surgery, while naturopathic oncologists have additional schooling in diet and nutrition. Dr. Noe also suggested we research medical marijuana, and so we did.

In researching medical marijuana, we learned about the scientific basis of how two key compounds, CBD and THC, derived from the cannabis plant, affect the human body and cancer cells. The body has twelve systems that work together (circulatory, nervous, digestive, etc.). The endocannabinoid system (ECS) was discovered in 1992 by scientists studying how cannabis interacts with the brain. CBD and THC are compatible with the receptors in the ECS. This previously unknown molecular signaling system is involved in regulating a broad range of biological functions and maintaining homeostasis, a healthy equilibrium, within the body. Scientists realized that the ECS allows the body to send signals back and forth, rather than just one direction, allowing the body to communicate with itself, so that it could fix itself.

While CBD and THC do not comprise a proven cure to cancer, they can help fight against the disease. They have demonstrated the abilities to prevent cancer cells from

reproducing, to prevent the formation of new blood vessels needed by a tumor to grow, to prevent cancer from spreading to other organs, and to cause cancerous cells to kill themselves. There are documented cases of cannabis oil sending cancer patients into remission, and there are cases of patients who took cannabis oil and still succumbed to the disease. There was nothing to lose in trying it.

Neil decided that he and I should apply for medical marijuana cards; I had to apply for a caregiver card. The Slater Compassion Center in Providence provides cannabis for seriously ill patients who may not be able to afford as much medicine as they need for their condition. We consulted with a couple knowledgeable staff members, and they provided samples of CBD capsules, CBD/THC bud blends, for vaping, and a couple tubes of a thick highly-concentrated cannabis oil, particularly high in THC. Finding the right dosage and balance of CBD and THC required guesswork, time and patience.

Ultimately, we hoped the naturopathic protocols and medical marijuana would slow down the cancer's development, while we researched and applied for clinical trials. Clinical trials are experimental in nature. They come with risks, and no guarantees.

We identified three interesting options open to patients with DIPG. Memorial Sloan Kettering in New York City was offering Convection Enhanced Delivery (CED), the targeted delivery of experimental drugs directly into the brain. The University of Louisville was offering an Immunotherapy process intended to train the immune system to attack cancer cells. The Burzynski Clinic in Houston, TX, was offering antineoplaston therapy. The Houston trial was the only one not requiring prior radiation and a biopsy report. Its trial protocol

was designed to test a peptide therapy, which had been used in previous trials to treat DIPG and *glioblastoma* (GBM) patients with some indication of success.

In 1967, Dr. Burzynski identified naturally occurring human peptides which are present in healthy patients and deficient in cancer patients. Concluding these peptides played a role in preventing the growth of cancer cells, he developed synthetic analogs of the naturally-occurring amino acid derivatives, peptides, and carboxylic acids. He named them *antineoplastons* (ANP). He claimed ANP therapy would alter the expression of more than 100 genes that affect tumor cells, switching off certain genes that cause cancer (oncogenes) and activating genes that fight cancer (tumor suppressor genes), while posing no harm to healthy cells.

In 1977, Dr. Burzynski opened the Burzynski Clinic to focus on treating terminally ill cancer patients, primarily those who had tried conventional cancer treatment and were not cured. In 1990, he began combining ANP therapy with additional drugs to provide “personalized therapy.” what has since become known as personalized therapy to better target more genes.

Fast forward to 2016, the Phase II clinical trial using ANP therapy specifically for DIPG patients was set to launch in mid-April. Through the internet, Neil's sister, Evie, turned over one final stone, discovering a DIPG survivor in Argentina who had been cured by Dr. Burzynski's ANP therapy. Evie and Neil managed to connect with Celeste Sebaugh through an online video session, and she told them her entire miraculous story.

Celeste's story is referred to as *anecdotal* evidence. Such evidence relies on personal testimony, and so its value is disregarded by the U.S. Food & Drug Administration (FDA)

and by practitioners of conventional medicine beholden to the FDA. Anecdotal evidence does not qualify as scientific evidence. Its highly personalized nature actually prevents it from being investigated by the scientific method. There are a handful of anecdotal DIPG success stories, yet conventional medicine has no clinical trial evidence of any successful treatment to date. This is the nature of the modern medical beast. Nonetheless, when one is diagnosed with a disease qualified *incurable* by conventional medicine, anecdotal evidence of success shines a small ray of hope like a lone island light house appearing out of nowhere on the darkest of nights.

We received a packet of materials from the clinic. The tagline below the clinic logo is “First, Do No Harm!” which is interesting, given the devastating side effects of most cancer treatments. When Neil was 12 and Evie was 14, they had witnessed the effects of radiation and chemotherapy on their grandmother Carolyn. There was an unbearable hotness beneath the soles of the feet that made it difficult to walk. There was the fatigue and the hair loss. There was the loss of taste, which was particularly notable, because she was an excellent cook and took great pleasure in flavors.

The tradeoff for Carolyn was that the treatments gave her a reprieve of roughly a year, before the cancer returned and took over her body. We all remembered her last Christmas, when we gathered to celebrate in her bedroom.

When Neil was diagnosed with cancer, we knew the seriousness of the situation, and we had no false illusions. Treating the brain was no light matter. We read a number of scientific studies documenting the results of ANP therapy. Dr. Burzynski had published these in various medical journals. We

understood that ANP therapy offered no guarantees for success. It was, however, the only pathway at the time that seemed to offer *possibility*.

We prepared to fly to Houston April 12, and reserved a hotel suite located near the clinic. Neil would undergo treatment as an outpatient, reporting into the clinic everyday. Before leaving home, Neil received three charms to help him keep the faith. His high school girlfriend, Anoush, gave him a gold Miraculous Medal, handed down from her grandmother to her mom, who was a cancer survivor. His school friend, Alex Goldstein, gave him a Star of David. And, Dean's best friend, Mike, a former Army Ranger, gave Neil his dog tag and his boonie hat – a wide-brim *hat* commonly used by military forces in hot tropical climates. We were ready to stand our ground in Houston.

When people are in deep trouble, they often turn to prayer. Being more practical and philosophical than religious, Neil sat propped up in his hotel bed, with his computer in his lap, researching Buddhism and meditation. In Buddhism there are four noble truths - suffering, the cause of suffering, the end of suffering and the path to end suffering. Meditation is that final path. Beyond the spiritual benefits of meditation are the scientifically-validated reasons to meditate. These include boosting immunity, reducing pain, and decreasing inflammation at various physical levels, as well as decreasing anxiety, stress, and depression on an emotional level. Fortunately, Neil was born with a contemplative nature, and, in the face of his terminal illness, meditation came naturally and led him down a pathway to a deeper level of insight.

While figuring out how we were going to turn Neil's darkening situation around, we sought out some light-hearted diversions in Houston. The most memorable of these was a restaurant, Ruggles Green in City Centre. It offered a menu of healthy options and outdoor seating that overlooked an astroturf village green. While waiting for our dinner order the first time we went to Ruggles Green, Neil sat down on the retaining wall that surrounded the green, and he watched the activity. One parent was chasing a small child in a game of tag. Several older children sat on the turf listening to a musician. Three young girls were dancing. A couple boys were throwing a ball. Other children were just running around for the pure love of running.

A tiny toddler, with the soft fuzzy head of a baby chick, was wandering aimlessly amidst all the activity. Angels must have been watching over him, because, miraculously, he avoided getting knocked over. All the bodies were weaving in and out

with perfect harmony. Neil was mesmerized, and he commented, "I've never seen anything so beautiful." In spite of what was happening to our family, there was still joy in the world; joy was everywhere.

Neil sat on the wall in a blissful state of "being." It was a cathartic moment that allowed him to release the fear and anxiety that had been building up within. In that moment, there was no traumatizing past nor dreaded future. There was just "now," and this thing called "life."

Around this same time, Neil reached out to a college chaplain at Northeastern University, Harrison Blum. Neil sent an email with the subject title "Looking for Guidance." He had attended a group Intro to Mindfulness class that Harrison had taught the previous fall. In the email Neil shared about his cancer diagnosis, and of a recent powerful meditative experience, a broadening perception and perspective, that he had had and was trying to understand. Through phone conversations and email correspondence, Neil and Harrison began a deeply personal exchange that helped Neil sort through many complex thoughts and emotions. In the memorial service held for Neil at the university, Harrison Blum shared the following words.

"At first Neil focused on understanding, on defining his temporary glimpse of something greater. Was it Truth with a capital T? Was it a taste of enlightenment? How could he return to that state? While validating the impact of his experience, I gently guided him to reflect on what that experience meant to him rather than how to define it. One theme of our conversation thus became the importance of living life fully rather than trying to fit life into defined

boxes. Another idea we explored was how to be more and do less. For Neil, in the context of moving forward after his powerful experience and within his illness, this meant being fully present with each moment as it was rather than efforting to return to some other, special state. As Neil put it in an email, 'I'm not sure the experience is yet over, as I've kind of felt myself going in and out of this state at what seems a bit like random. I definitely think it has to do with the zen mindset of taking one moment at a time.'"

*All of this makes me think about how the most meaningful gifts we bestow on others are spiritual rather than material in nature. The gift can be a listening ear or a thoughtful word. The following story, **Gifts of Wisdom**, speaks to the amazing power of thoughts and words.*

GIFTS OF WISDOM

Houston was a long way from Boston. Distanced from his college friends and pursuing an experimental cancer treatment, Neil kept in touch through texting and social media. One friend, Madeline, posted a video of herself reading The Jester Has Lost His Jingle, and Neil replied:

“Oh Madeline, I love you. You truly are a one of a kind. And howd you know I love that book? Haha From the time of my diagnosis the coincidence of this book always seemed strangely funny to me. I got my own copy in the mail from Barbara Saltzman, and it was a surreal feeling after having worked so closely with the Jester and Pharley Phund. Anyways, thank you for the Buffalo! I havent heard that in way too long, definitely brought me laughter! Thank you Madeline!”

Events in the Jester's story mirrored those in Neil's own life. The book began with the verse, “Our story begins quite removed in a castle far away./Our story unfolds, unfortunately, on a very unfortunate day.”

Another friend, Rachel Record, posted:

“Hey Neil!!!! I'm so sorry that you have to go through what you are doing right now, you are one of the sweetest, kindest, most thoughtful, most caring, and bravest people on the face of the Earth. I

wanted to let you know that although it's been quite some time since I've been able to see you, you've inspired myself and so many others to be brave in so many ways, big and small. The magic note you gave us all 2 years ago at SLTP is one of my all time favorites. It inspired me to be brave daily, as well as when called upon. Your words inspired me to run for regional and state student council boards, and to leave the podium and speak to the audience whilst doing so. I've been told by many that those speeches inspired them to be brave at home, and every time I hear that it makes me think of you and this note. You've changed the lives of more people than you know. Thank you for being brave, and teaching all of us how to be so too. I love you so much, keep being the strong, brave person you are, and I hope to hear some more good news from you soon!!”

Rachel attached a photograph of a note Neil had given her:

“My gift to you is an African symbol that stands for Bravery and my wish for you is to be brave. Bravery is a thing that is often looked past in society today. Many people would rather just get by under the radar, without standing out. My wish for you is to not be afraid of the judgments of others. Believe in yourself and do what you know is right. Actively follow your dreams and don't let the fear of failure deter you from your success.

Being brave means standing up for what is right even if you are standing alone, it means giving everything your all and not settling for a half-hearted attempt. Be brave and remember we believe in you! Love, Neil"

Neil had given Rachel this symbolic gift in an exchange that took place among his team of student leadership trainers at a special staff meeting. Neil had returned from that meeting with a paper bag filled with the symbolic gifts he had received from others. As I looked through this bag of simple gifts, the item that grabbed my attention first was a small crushed red box. I could tell it used to be a perfect cube. There was a red note sticking out of the box. I pull it out and read:

This box is a reminder of the humor skills shop from earlier this week, where we learned about the humor pyramid and how to use humor as a tool to build and not break down. Keep this box around for those days when you wonder where laughter had been hiding, and remember it's hiding inside of you (not actually inside the box).
~ Mina

Mina's message was referring to the last line in the children's storybook, The Jester Has Lost His Jingle: "So when you're feeling lonely or sad or bad or blue remember where laughter is hiding... It's hiding inside of YOU!" I paused to

think about how happiness *is* a choice... all things happen for a reason, and we must try to find the good in it all. It is a challenge to find the good, or even the humorous, in an unfortunate circumstance. Cancer is not a laughing matter, yet many people, when faced with cancer, turn to laughter as the best medicine. Humor can lighten the heavy load. And so, cancer becomes the perfect excuse to tell jokes, watch comedies, and read funny books.

Humor was one of the most important lessons in Neil's student leadership training. He learned how humor can either include or exclude people. Sarcasm excludes, divides, and victimizes. Sarcasm undermines trust. SLTP's Stepping Stones program explained humor's dark side, "Humor can just as easily and just as quickly divide a group, hurt an individual, single out someone, ostracize others and offend the rest. Hurtful humor tends to bring out the worst in someone. Healthy humor tends to bring out the best." Training emphasized laughing **with, not at**, people, and it cites a quote by Mark Twain: "laughing with people encourages togetherness, laughing at people creates division."

I set the red box aside and picked up a pink slip of paper with a nail taped to it.

CONSIDER how you
spend your TIME, your
DAYS, and your
LIFE.

What do you create
with your ACTIONS,
WORDS, and
THOUGHTS?

Are they POSITIVE?
PURPOSEFUL?
What can happen
when you choose
to be
CONSTRUCTIVE?
WHAT CAN YOU
BUILD?

For Neil, building a better world was not so much about working with nails, wood, bricks, and machines. It was more about working with people, inspiring people's problem solving abilities, building people's relationship skills, and showing people how to work better together.

Another note had a small rectangle of balsa wood attached to it. The rectangle had a black dot near the middle left edge. I read:

“When you begin to touch your heart or let your heart be touched, you begin to discover that it's bottomless, that it doesn't have any resolution, that this heart is huge, vast, and limitless. You begin to discover how much warmth and gentleness is there, as well as how much space.” Pema Chödrön

My wish for you at the beginning of this week was to decide that you are limitless. My gift to you is a door to remind you to open up your heart and your mind. Each of you is huge and vast and limitless with an endless capacity for warmth and compassion and passion and action.

Around the time Neil was diagnosed, he was reading a book titled mindset, by Carol Dweck, about moving from a

fixed mindset to a *growth* mindset, from limited thinking to unlimited thinking. The book was timely. Neil's cancer was deemed incurable by conventional medicine, which is why he decided to look outside the box. He imagined that there was a cure out there somewhere for DIPG. His diagnosis became another life challenge to be overcome. His best friend Andrew Grady described Neil's determination in these words, "He was so adamant about beating this so that he could only further prove that anything was possible, and he soon had a step by step plan on how he was going to tackle this difficult task." The clinical trial in Houston opened a door of opportunity, which was the chance to actively participate in DIPG cancer research.

Another slip paper, with a Sudoku puzzle attached, spoke directly to the notion of challenges:

"Above all, challenge yourself. You may well surprise yourself at what strengths you have, what you can accomplish." -Cecil M. Springer

My wish for you at the beginning of the week was to challenge yourself. I asked you to push yourself even if it was awkward. You challenged yourself all week and truly grew and found out new things about yourself. My gift to you is a Sudoku puzzle. It is meant to remind you that no challenge is too hard and that you can accomplish it.

*Love,
Marcus*

Life brings many challenges. Sometimes one wrestles with a difficult topic in school – like calculus or physics. Sometimes one struggles with the insensitivity of peers or with a heartbreaking personal relationship. Sometimes one must contend with conflicting desires. Challenges are tests that help people learn and grow. That said, it's difficult to imagine a greater challenge than what Neil had to face. How was *cancer* supposed to help him to grow?

There was a Kit Kat bar among the items, and I found the slip of paper that went with it:

At the beginning of the week my wish for you was to dream big, have long term goals but then take those big ambitions and break them into little pieces you can work on every day. It's so important to have huge goals in life but sometimes our big dreams can feel really far away so my gift for you is a kit kat bar to remind you to break your goals into bite sized pieces so you can feel like you're making progress and be inspired to keep working at those big dreams little bit by little bit each and every day.

Love,

Dessie

While Neil's greatest dream was to create a better world, his more immediate objectives were survival and the advancement of cancer research. Anyone seeking to beat cancer learns how to take the situation one day at a time – little bit by little bit. The patient undergoes daily treatments, hoping for noticeable improvements in symptoms. Doses are

increased in tolerable increments to maximize effectiveness and minimize risk. The intermediate objectives are MRI scans showing no progression, or better yet, tumor shrinkage. The ultimate goal is **complete response**.

Next I picked up a message with a silver-edged beautiful blue butterfly sticker, and I read:

"And just when the caterpillar thought the world was over, it became a butterfly."

My gift to you is this butterfly. Each butterfly is unique. Each butterfly is beautiful. And, butterflies, much like you and me, cannot see the colors of their own wings, so they never know just how beautiful they are. Let this be a reminder for you to be optimistic. Better things are always coming. Bad days always end. And, at the end of the day, everything is in your power. You can choose to be optimistic. You can choose to be happy.

"Doing what you like is freedom. Liking what you do is happiness."

Please never forget how amazing, and beautiful, and unique, and special you are!
~ Dagny

Happiness is a beautiful choice, even when standing in the face of a difficult challenge. I have often thought it is the choice with the greatest potential to transform us.

Finally, I picked up a blue note with a small piece of white quartz glued to it:

"Lighthouses don't go running all over an island looking for boats to save; they just stand there shining."

- Anne Lamott

My wish for you at the beginning of this week was to be confident, in who you are and in what you can do. Now, I want you to remember the person you have been this week, and the leaders that you are. Be confident in yourself, and remember the enormous capacity for good that you have. My gift to you is a rock from the base of the lighthouse near my home. SLTP has given you solid ground to hold your own lighthouse on. Now it's time for you to shine.

The lighthouse is the person who can offer a gentle smile and light touch and say, "No matter what, I am here for you. No matter how dark it gets, I am here for you." This is the "God spark God power" that we all have within us. This is the power to help others through the darkness and over to the other side, to where there is an end to suffering. This is *love*.

When Harrison Blum spoke about Neil's spiritual journey, he referred to the light of love that shines in the darkness. Neil was and continues to be a light, and I know that he would want me to share Harrison's insights about life and death.

“In witnessing and connecting with Neil, I was profoundly touched by his ability to move toward rather than away from life at a time when his body itself was moving out of his control. This move toward life's fullness in a time of grave illness might seem counter intuitive or paradoxical, and indeed I would say it's rare, but as Neil wrote to me, 'I feel reaffirmed that these paradoxes are in fact not necessarily meant to be solved.'

“After these phone calls and emails, Neil and I met directly in person for the first time on what was to become one of his last lucid days. In the hospice center in Rhode Island I spent some time on a sunny Saturday afternoon, both one on one with Neil and with his sister Evie, mother Wendy, and father Dean. While Neil wasn't able to speak at that time, his eye contact was sustained, textured, and vibrant. Having worked as a hospital chaplain in intensive care settings with many patients unable to speak and in varying states of lucidity, it was clear to me that Neil was fully present, and more than that was interacting with me through his eyes, face and finger movements as we held hands.

“During that conversation, I offered prayer, silence, and affirmation. I named him within lineage, within a lineage of seekers, of those who behold life with a humble sense of wonder. I also spoke with him about death, acknowledging that his death may be approaching

soon, and he held my gaze with a steadiness that spoke to me as continuing to be fully present with life, even as life was leaving him. It's an unusual person who can do most of the talking, most of the teaching, without even speaking in a conversation, and that's how Neil was with me that day.

“Once his family returned to the room, we read a passage from the Daily Word pamphlet and discussed the importance, and perpetual trickiness, of getting out of our own way to experience our Christ Consciousness – this sense of broader meaning and connection from which Neil seemed to have been speaking over the past many months. I so appreciated the warmth, the love in that room, even amidst the hard emotions that were also there.

“And I'll use this idea of love amidst the heartache, of light shining into the darkness, as a segue into Neil's response to a quote we connected around, and that I'll close with. The quote is from the early 20th century Austrian poet Rainier Maria Rilke, who wrote,

“Be patient toward all that is unsolved in your heart and try to love the questions themselves, like locked rooms and like books that are now written in a very foreign tongue. Do not now seek the answers, which cannot be given you because you would not be able to live them. And the point is, to live everything. Live the questions now. Perhaps you will then gradually, without noticing it, live along some distant day into the answer.’

“Upon sharing that quote with Neil, he responded to me via email:

“I totally get what that quote is getting at, which really excites me! I have been doing some deep soul

searching and spiritual awakening which yielded some truly jaw dropping findings. Nowhere near having all of my questions answered by any means, but that wouldn't be fun. What I did find is exactly what that quote highlights, a way of living that makes the most of every moment no matter the circumstances.”

*There is a book by Eckhart Tolle, The Power of Now, that explains how by entering the “now,” we overcome our own ego and, in so doing, gain access to the most extraordinary of truths: that we are literally one and the same with everything that exists. As Neil completed his leadership training, he learned to relish the “now” moments with his peers. And, in doing this, he achieved a level of leadership that supersedes ego. The next story, **Unassuming Leader**, shows what this kind of leadership looks like.*

UNASSUMING LEADER

Neil was never a “popular kid,” nor a sports team captain, nor a student council officer, however, he was influential. In SLTP style, he enjoyed being in the middle of team activities, where everyone belonged and everyone had an opportunity to lead, or not, on their own terms. He took the skills he learned through Student Leadership Training Program experiences and thoughtfully adapted them to his own subtle style of leadership.

His service portfolio held unusual documents of recognition. He earned SLTP awards for Fundraising and Collegiality, as well as The Peter J. Baltron Award for “personal development demonstrated through contributions.” He was honored with the 2014 Student Leader of Honor Award in recognition of his “positive contributions, extraordinary commitment and dedication to making difference for school and community.” I also found an unexpected letter of acknowledgment from the high school principal.

“Thank you for the extensive amount of analysis, research, and preparation that went into the workshop you developed and facilitated on Wednesday, January 4, 2012 for faculty members at East Greenwich High School.

“As you know, a primary recommendation from the NEASC accreditation committee requires us to engage a collaborative process, which includes teachers and students, to develop a set of core values and beliefs about learning. The process you undertook to analyze student

survey data for recurring themes, and to develop what you so aptly defined as a set of “positive, enduring, and meaningful” values was comprehensive and professional. To leave a group of senior faculty members speechless is no easy feat, and a testimony to the quality of your presentation and the substance behind the value statement you drafted. You can be assured that the value statement ultimately adopted by the high school will remain true to the tenets you so thoughtfully crafted.”

Neil also brought his leadership skills to one-on-one conversations – listening, empathizing, questioning and brainstorming alternatives. Beyond all that, he discovered his ability to influence others with the smallest of gestures. When Neil applied for National Honor Society as a junior, he wrote the following in his essay on leadership:

“As a student at East Greenwich High School and a person on this Green Earth I see it as my duty, to be the best that I can be and to help people in any way I can. I do my best to be kind and compassionate to all, and I'm not afraid to care. I just love to help. It doesn't matter how small a thing. It could just be picking up a piece of trash left behind after lunch, trying to cheer up someone on a bad day, smiling at people as I go down the hall, or helping someone with a chemistry concept they don't understand. If I have the ability to make someone's day better or to help positively affect someone's life, what excuse do I have not to? Because at the end of the day it's not about me, it's about the world I leave behind me. That is just a snippet of my personal philosophy and some insight into the values of the leadership program I am a

part of. Thank you for your time and consideration for National Honor Society. ”

Three months after Neil died, someone sent me a copy of the tribute that Mr. Lenox, the high school physics teacher, had delivered at the school's 2017 Honors Night. It was an annual event that celebrated juniors and seniors who earned National Honor Society recognition, academic awards. and college scholarships.

“Thank you for coming this evening to our Induction Ceremony. Also, congratulations to our new Inductees and to our graduating seniors. I envy you for having so many opportunities ahead of you. Henry Adams, of the historic Adams family from Boston, once said; 'A teacher affects eternity: no one can tell where his (or her) influence stops.'

“I’d like to offer a corollary to Mr. Adam’s statement: “A student can have a lasting impact on his or her teachers. No one knows how far a student’s influence can extend.” How much does a student impact a teacher? (Ahhh, if the walls of the faculty lunchroom could talk!) We share your silly remarks; we ponder your insightful comments; and we pass along your discoveries.

“East Greenwich 2014 graduate Neil Fachon was that kind of student. He excelled in chemistry and physics, loved to play chess and many other board games. To balance out his academic side, he played varsity soccer and tennis. But above all, he had an infectious smile.

“In 2016, Neil was diagnosed with brain cancer and his condition declined rapidly by the end of the year. I visited with him during this time and shared with him his NHS Personal statement... the same essay prompt each of you responded to. In regards to leadership, this is what he wrote:

“Leadership is often a very misconstrued thing. Most people think it’s about being at the head of something with people following you. A leader is often looked at as having power and control... Leadership, however, is much more profound and filled with many more dimensions than most might think. I often look at leadership from the inside out. True leadership comes from building your own being and willingness to be the best you can. It revolves around striving and aspiring for personal excellence academically, relationally, and morally. Leadership, in broad terms, is about being the most positive role model you can be and about having the most positive effect on the people around you as you possibly can.’ This sums up what every NHS member should strive to be.

“Following my visit, I was compelled to share these words with friends: ‘Today I visited a former student who is in hospice care. In the time that I spent with him and his family, I learned a few lessons. He showed me the strength of a family that stands by your side, even in the most difficult times. He taught me the power of a smile, such that it would erase any sense of pity or discomfort I might feel for him. And he reminded me that life is worth every breath, no matter how difficult. I am not surprised that he has taken the lead - he, the teacher; and I, the student. He was that kind of person in high school.’

“The reality is that each of us could strive to be like Neil, but ultimately, we would fail. He was unique. He had chess skills that were reminiscent of a young Bobby Fischer, but unlike Fischer, he had a personality that brought people together. He could talk about chemistry and physics in a way that encouraged conversation, not stymie it. Quite simply, Neil had a gift. If Neil were here today, he would convince all of you that you have a gift and tell you to discover your gift, and find every opportunity to give it. And if the opportunities are limited, then create your own... start a club or make a video. Who knows, you may have a lasting impact on a teacher, who in turn, passes that experience on to countless students.

“Neil embodied the attributes of character, leadership, service and scholarship; and your induction tonight requests the same from each of you. This is what it means to be a member of the National Honor Society.”

During his senior year, Neil was in Mr. Lenox's Advanced Placement Physics class and was also a member of the Physics Team. While visiting Neil in hospice, Mr. Lenox brought photos of the team, taken when they had participated in the Physics Olympics at Yale University. Neil's smile beamed in every photo.

48 different high schools competed in the event. Students had 45 minutes to complete each of five challenges, the details of which were kept secret until the day of the competition. The purpose of the event was to give students a taste of the science they could pursue in college and beyond *and* to highlight the impromptu nature of real science problem-solving.

In any given year, challenges might involve measuring an unknown quantity, optimizing a process, or constructing a device to perform a function. One activity was always a quiz consisting of Fermi Problems, which require combining quantitative guesses to produce a fairly accurate final estimate of some unknown number.

Prizes were awarded for each event, and there were spirit prizes too for best costume or t-shirt and best team name! Neil's chemistry teacher, Celia Schnacky, made cat ears and tails for each team member. The team named themselves Schrödinger's Cat, after a famous hypothetical thought experiment in quantum theory, which states that atoms or photons exist in multiple states that correspond with different possible outcomes. Is the experimental cat inside the box dead or alive? Do the observer and the cat exist in two realities – one in which the cat is dead, and one in which the cat is alive? Or do the observer's thoughts, in the form of expectations, convey energy to reshape matter and determine the outcome in the observer's reality? These are the types of questions Neil loved to ponder. If someone no longer existed in this reality, could that same someone still exist in an alternate reality?

The team failed to place in any one of the five events of the competition, however, they had a lot of fun, which included a super fun surprise in the end. When all their points were tallied up, they won third place for the overall competition.

Neil was interested in learning about many topics, and environmental issues were top among those things. He wanted to help tackle some of these problems. Dean recently found a thumb drive that had fallen behind some furniture in Neil's room. One of the files contained a list of "Biggest Environmental Issues" that Neil had compiled on June 9, 2014, upon graduating from high school. Here are some of the items he wrote on that list:

Toxins

- Fukushima – Radioactive waste
- Pesticides, herbicides, fungicides, oil
- Soil contamination
- Landfills
- Recycling/Reusing
- Sustainability

Ecosystem Destruction

- Deforestation
- Species endangerment and extinction
- Invasive species
- GMOs
- Coral Bleaching
- Ocean Pollution/Overfishing/Extinction

Air Pollution

- Depletion of Ozone
- Smog/City Air Pollution – Cars, factories, power plants,
- etc...
- Changing Climate

Depletion of Natural Resources

- Carbon Footprint

Overpopulation

Land use and allocation

Food safety

Genetic Engineering

Pesticides

Preservatives

Mining

Fracking

Nanopollution/Nanotechnology

Water Pollution

Drinking Water Contamination

War and Military Munitions

Refugee Influx

In addition to being big environmental issues, these are also human health issues, leading either directly or indirectly to the development of cancer and other diseases.

Neil was also interested in learning about space exploration – inner space perhaps more than outer space. He was fascinated with the brain, psychology, the development of the mind, the process of thought and how it all worked. It seems so strange to me that he came to be diagnosed with brain cancer, which led him deeper into learning about this particular topic.

*When he could no longer speak, I wanted so badly to know what he was thinking, because he always had deep insights to impart. The next story, **Revelations**, shares some of Neil's written reflections on life, love, liberty, humanity, yin and yang.*

REVELATIONS

Neil received a journal as a high school graduation gift. On Monday, June 9, 2014, he wrote about his state of being:

“Just got this journal as a graduation present from Aunt Suzie and Chris. Hopefully I can get into a habit of using it, but, knowing me, I probably won't. Oh well, we'll see. So graduation yesterday... Feels weird. I'm still in shock I guess. Idk what to think or feel. Everything just seems weird. I can't really think straight either. Stuck in that slightly hopeless, emotionless, and dispassionate state. Lil Bear [Neil's pet hamster] has to get surgery tomorrow too. Hope that goes well. Fingers crossed. Bleh I wonder if I'm just weird or have a chemical imbalance every once in awhile.

Well, on a brighter note, I was hitting well today [tennis], even if it was semi-lazy. I had a good stroke though. Feeling the improvement...”

Neil filled 19 pages in the journal before setting it aside six weeks later. He poured his innermost thoughts out onto the pages, and reading the words now brings Neil back, more deeply, into my heart. On Sunday June 15, he wrote about many things. He wrote about how he felt about the state of the world:

“I feel like I am learning so much about myself and the world everyday yet I feel like I still know nothing. There is so much I wish to understand about the world which I know

I probably never will. Though I seek to understand anyhow. We went to the Cape today to enjoy a Father's Day with Grumpa [Grandpa Gene]. It was a very interesting day filled with many thoughts and deep emotions. Looking at Grumpa's dying oak trees (due to some type of wasp) I couldn't help but feel the inevitability of human presence and interference and its effect on nature. This invasive wasp killing my Grandpa's trees is merely a metaphor for the invasion that humanity has had on nature and our world. We are like this invasive wasp in many ways. Too much of anything rarely seems to be a good thing.”

He wrote about love:

“We took a ride to Shibui later to relax and to rest our seemingly weary limbs. On a whim, I picked out the movie Braveheart and began to watch. It's with the start of this movie and the loss of William's wife when I began to question myself. It may be only a movie but that was love... a much deeper connection that went well through the skin. I love and care for my friends, my family, my world, those people I've never met, the people that I never will meet, all ancestors of all living on this planet who are long lost, every being and creature that lives on this world. I admire all in their ability to create their perspective to see and gift to the sands of time. I care about where my world, my universe is now and where it is going, yet I don't feel I understand what it means to love. I feel so naive to it and what it means to truly love with every fiber, strand and particle of ones being. I hope I know what this feels like one day. What it feels like to love without condition and to

believe without doubt. I may never be able to achieve this but I believe it is one of my deepest wishes in self indulgence to do so.”

He wrote about freedom:

“Freedom. What is it? We view it as the ability to make choices of and for ourselves, so we may live our lives as individuals with free will. Yet it would seem that humanity's freedom has led it to the brink of chaos. I think freedom is the right to live a natural life unimposed upon by others. But to true freedom there is more than one's own freedom. To true freedom one must understand the freedom of others and in so doing respect all others with their freedom as deeply and dearly as we hold our own. This includes protecting the balance of our world because if we do not, we eliminate the freedom of all Earth's occupants. I wish I could understand and interpret this deeper but it gets confusing. Maybe what I mean by freedom comes back to Yin and Yang. There is a balance to everything, even freedom.”

He wrote about peace:

“Just before leaving the Cape, I stood up on the hill and looked out upon the water. A sense of peace unlike one I've ever felt before came over me. Looking up at the clouds blowing with the wind, I felt like I could see the world floating by. The world actually seemed like a sphere in this moment. And with its humongous belt, the world felt small. It was a feeling of the purest peace I think I've ever felt....”

He wrote a about family:

“After that we grabbed a bite at Crab Apples before taking the first walk on the beach of the summer. The sand felt good between the toes and the wind and water lulled the senses. Along the walk I waded knee deep out to a sand bar. The separation from the “mainland” for the small time felt nice. I loved going on this walk with my parents. I love mom and dad so very much. And I know they love me as well, the feeling attached to this I imagine I still can't fathom, but also hope to feel this some day. When we finally got home, we finished Braveheart and just before going to bed I gave dad a great big father's day hug. I should do that more often, not just on Father's Day. Well good night. Thanks for lending me your pages to help me mull things over in my mind.”

On June 21, Neil wrote about a “Bad f**kin day.” Everybody has them. Then he set the journal aside until Saturday, July 19, when he wrote about the absolute best day:

“Its been awhile since I wrote in here but I think today is a day worth writing about. I feel like I turned into a man today. Maybe it's the lack of sleep talking, but something feels different. I feel like I have become someone that there is no way I could ever be. I'm just not this good. This is someone else being praised, not me. It's been an out of body experience. These people can't possibly be talking about me, I'm not this good! But somehow they are. I have made a serious difference for a lot of people and all without knowing how. I never even thought I did anything that big.

I feel like after all this searching I've finally found myself...

“Leading off a different train of thought, the fact that I have seemingly accomplished so much yet even though I didn't realize it or feel like I deserved it. I didn't want these compliments because I felt like they were above and that is why I think I may have actually deserved them! I put others before myself and lived in the purest form of 'we' rather than 'I.' And I still don't believe I am worth this high praise, and I think that's cool. Recognition, praise and affirmation is given to those who truly give selflessly and relinquish their ego to do so. It's when I truly believe with all my heart in others that I become my best self. By wanting recognition for my actions I don't feel I am deserving of said recognition. I have grown and learned so much this week I think it is just incredible. True meaning has been brought to the statement 'I am,' because we are. I am proud to be me whoever that is whether it be body or soul or both united.

“It means far more to love than to be loved.”

What happened to make Neil feel so amazing? He had just returned home from leading his last SLTP camp session. He had been assigned to the A-Team, which meant he was responsible for making sure the whole week of camp ran smoothly for all the staffers and all the campers. This was the biggest leadership responsibility he had ever been given, and he knocked it out of the park. I figured this out by reading through that summer's bag of magic notes.

Neil,

I am so lucky to have you as my teaching partner. You are always asking how you can help, always willing to the the extra mile to help out in whatever way you can. You not only do whatever is asked of you and then some, but you do it with passion and a fabulous sense of enthusiasm. You have impressed me so much this week and exceeded my expectations in a big way. Thank you for taking so much weight off my shoulders. You were a wonderful partner this week, and I couldn't be more proud and grateful.

Mary

Another magic note was written on a piece of paper that resembled a \$100 bill and was imprinted with a story:

YOU ARE VALUABLE

The teacher said, "Who wants this dollar bill?" Several hands went up, but the teacher said, "Before handing it over, there's something I must do." She furiously crushed it, and asked again, "Who still wants this bill?" The hands continued raised. "And what if I do this?"

She threw it against the wall, letting it fall to the floor, kicked it, stamped on it and again held up the bill, dirty and crumpled. She repeated the question, and the hands continued too be held high.

“You mustn't ever forget this scene,” said the teacher. “No matter what I do with this money, it'll still be a one dollar bill. Many times in our lives, we are crushed, stamped on, kicked, maltreated, offended, however, in spite of this, we are still worth the same.”

Handwritten next to the story were these words to Neil:

What Jim said hit the nail on the head. You left me in awe this week. We could have easily dropped so many balls without you. You were the glue this week. Thank you.

I ♥ you Brittany

There were many other notes, and here are the words from some of them:

Neil,

Your work on the A-Team was amazing. I felt I could reach out to you for advice or help and saw you do your best to help me out. Thank you for all of your work that wasn't seen this week as well. You truly put the staff and campers ahead of your wants and needs.

Love John

Neil,

What can I say, you're like a brother to me. Without you, my whole SLTP experience would never have happened. What you have shown me and taught me will never be forgotten. You have taught me to reach outside my comfort zone because every time I do that a new light turns on inside me. You have shown me that taking positive risks is very important because when I do that others will follow. You have shown me that leadership isn't just being a nice guy and knowing the right thing to do, but it's doing the right thing and going the extra mile to make sure people remember how kind you were to them so they will repeat it to others. More importantly, I think you have taught SLTP a lesson. You have taught them that anyone can rise to be a student leader. You were willing to take the leap of faith, and that has paid off for everyone in this camp. Because of you, more people will move forward. Not just in leadership, but in a school setting, or in their job perhaps. The possibilities are endless. Don't stop leading; everyone has something to learn from you. Love your little cousin,
Chris Kalweit
Looking forward to more tennis!

Dear Neil,

I really realized the full extent of your talent, you are a truly special individual, that is a real leader and I am honored to have you as a real friend... you poured your

heart and soul out during this conference and it was quite a show. No joke. I also want to say just WOW. There is too much to say on this little shred of paper...

Alex

Dear Neil,

The first familiar face in a crowd is always a great source of comfort and for me this week that was you. It was great seeing you again and chatting a few times. In my opinion, you were the ideal model of the A-team staffer. You were always pleasant and always very present. If they needed something, you did it. Not to mention you still have that high octane energy that was difficult to match. Enjoy your summer and freshman year of college. You'll be great!

David Orsi

I'm glad I had you as a familiar face this week, it made getting comfortable on the first day a lot easier! Thank you for always being so thoughtful, whether if it was in a discussion or sitting next to me because you realized we hadn't chatted in a while! Your awesome energy and enthusiasm definitely transferred to everyone around you and even though you had a lot of

work to do, you always trundled around with a smile!
Good luck at college this year, I'm excited to hear
about all of the amazing change you bring to your
community there!

Love, Keira M. (seaside)

*Dear Neil, roomies 4 lyfe. Your energy and
intentionality this week were so great. I loved that I
could count on you for energy and laughter. You
brought reassurance to even the most hopeless of
campers. Thank you for keeping me and everyone
else positive.*

Graysen

Dear Neil Fachon,

*OHMIGOD NEILLLL! Who would have thought that we
would be in the same week of SLTP? You were absolutely
the best throughout the whole week. You were really
damn chill yet at the same time, one of the most
enthusiastic staffers out there. Also, you give FABULOUS
hugs!*

Love ya,

Zane Yu

Seaside

*Neil I love your personality. When you go from crew to
crew you light up a room. Everyone smiles whey they*

see you. Your positive attitude really inspires me. I like how you are not afraid to be yourself, like how you were doing all those awesome dance moves at the social. I think that you shined your light brightly throughout the week.

Love, Verena Seaside

Neil,

I loved how nice you were from the start and how you'd pop into different groups to see what's going on. Also it's cool how you think people should always do something different and their own thing because every person's different.

Danielle

Neil – You were one of the first people I met. I thought you were adorable. You were kind and encouraging to me. You made me feel special and welcomed. You also looked super good at the formal dinner.

XOXO Julianna

Neil

You are really funny. Thanks for making this week possible. It has been a really fun time so thank you. You have changed my life.

Alysha Woodlands

Neil,

On the first day you were one of the first people to come over and talk to me. I really like how nice and inviting you are. Your personal theme is Be Brave and I definitely tried to be brave this week. Thank you for everything you did for me!

Stacey

P.S. You are an amazing leader and person! You made a HUGE difference in my life!

Neil,

Thank you for being so kind and friendly to me this week. You seem like someone who is really old (in a good way!) and has a lot of knowledge to share. I only just realized that you are not that much older than us and you were in our position. I think you are really approachable and easy to start a conversation with, and one that isn't forced. Also, I liked your lightening rhyme (I must have because it's been stuck in my head since you sang it),

Sophie (Desert crew)

Neil,

A flicker, a flash, a BOOM AND A CRASH! You were super enthusiastic in the past five times. You were an active learner and always helping others.

Vincent

Neil!

I remember you saying you wrote 3 of the verses to Boom Chick a Boom and they were really good! My favorite was the soccer one! This week you have been a wonderful friend to talk to and depend on for a beautiful smile.

Abby

Neil,

Whenever I look at you, you have a smile on your face. It's a warm smile that says, you care. You're always helping, encouraging and supporting. You are a true leader. You may not always get the most recognition, but without you, SLTP wouldn't be. Thank you for your devotion, hard work and effort. It does not go unnoticed. :) You are so kind, caring, intelligent and wise. I know that I will see you in the future, but let's stay in touch. :) For now, follow your dreams and

*don't let anyone stop you. Just keep swimming, you'll
get where you need to go. With all the love in the
Universe,*

Rachel Record

The young man, who once worried about having “no friends,” went on to live a life full of tremendous love. Love. It means far more to love than be loved. Love is more than a feeling. In its purest form, love is an action. This is what Neil learned through his SLTP experience. We never love so completely as when we give our care and attention to someone in need. And, the more love you give, the more you receive in return.

SLTP was the best thing to happen to Neil as a teenager. Shortly after his passing, I heard the sad news news that SLTP would be closing its doors. Founder, Jim Fitzgerald, who was the heart of the organization, had been experiencing his own personal health issues.

*Sometime after graduating from high school and completing his time with SLTP, Neil created a document titled **Neil's Words of Wisdom**, which included the following statements:*

- Passion is imperative
- You are in control of your own life.
- Don't be distracted from the real world.
- Live in the present but for the future.
- If you aren't present in your life you're not in control.
- Relate to her world.
- Have confidence in yourself.
- Everyone has a story.
- Leaders are made through action.
- Commitment, passion and belief is the foundation action.
- Be spontaneous. Not everything is meant to be planned.
- All things are relative, even advice.
- Judgments and opinions help us make sense of the world around us but never judge a person in totality. You never really know a person until you walk in their shoes and face their demons.

- You can also never fully judge yourself as you can never fully see who you are until you've looked at yourself through someone else's eyes. ~ You are a complex creature.
- Focus is what gives life direction, determination is what helps ones stay the course.
- You are a biased creature no matter what, all you can do is realize your bias and seek to see past it.
- Don't stop chasing your dreams, or your dreams will chase you.
- Take time to think about the big picture that is your entire life and don't just get fully enwrapped in the problems of the moment.
- Imagine yourself conquering life and beating your fears. This act of imagining can help to make it a reality.
- Your reality is painted by your personal senses.
- Open you mind but focus your thoughts.
- Challenge your own ideas.
- “Fear is useless. What is needed is trust.”
- Failure is an important part of growth.

My hope in sharing some of Neil's SLTP journey and the wisdom learned during this period of his life is to inspire other young people. I want to let them know how much they matter and how capable they are of making a difference.

I continue to share The Jester Has Lost His Jingle in my own work with elementary aged children, and teach them the most important message in the book: “It's up to us to make a difference. It's up to us to care.” As part of Neil's legacy, Dean

and I have raised funds and awareness for The Jester & Pharley Phund and for Camp Sunshine. These are ways I can help spread the messages of hope, joy, love and the power of difference making, especially to people who face the darkness we faced.

*In the wake of each passing, angel messengers deliver signs of comfort to ease the further suffering of those left behind. Some people call these messages **after death communications** (ADCs). For those who ask and seek, these signs appear as responsive messages from dearly departed loved ones, assuring us that all is well. I have had ADCs channeled through friends, dreams, songs, synchronicities or found objects.*

Cleverly devised and delivered in response to my own heavy-hearted emotions, most spiritual messages are sent to me in material form, such as a lost book along a sidewalk, a donut-shaped cloud, or a luminous display of jingle shells on the beach.

I have received ADCs in the wake of the passing of other family members. One of the very first arrived two weeks after Grandma Carolyn died. It was a single yellow pansy. It popped up from beneath a snow drift in the middle of January, right next to the doorway into our house. In the language of flowers, the pansy means “thinking of you.” Every spring, Carolyn planted pansies in window boxes on the patio by her doorway.

*A whole string of ADC's appeared during the week after Grandpa Ferd's passing in 2013. The ADC's I've been finding in Neil's passing have out shown everyone else's in terms of cleverness, number and humor. To this day, his spirit continues to make me smile, laugh, stand in awe and think deeply. In sharing the following story, **Signs of Everlasting Love**, I share some final examples of this.*

SIGNS OF EVERLASTING LOVE

Grandpa passed away in 2013, and I received various *after death communications* (ADCs). One of the funniest arrived seven days after his death. I was looking out the window of the of the breakfast room, where grandpa used to sit and read the morning newspaper, and I spied a spider, darting away from the center of its web into the bushes. It moved quickly, as if I had caught it in the act of something naughty. Sensing an intuitive urge to investigate the situation, I stepped outside.

What I found was a perfectly spun orb web, and it had been carefully placed. The web was visually centered on the breakfast window, forming an optical delusion. The web created the appearance of a bullet hole, surrounded by shattered glass,



radiating outward from the hole. A shiver ran up my spine, as the meaning of the vision popped into my mind, “Sorry, honey. It was time to take him out.”

I captured the spider's creation with my camera, however, I failed to capture a photo of the spider. It was long gone.

During a later trip to Florida, Neil and I discovered the culprit. It was a horny-backed orbweaver. It has six sharp red horns that radiate out from its abdomen and a white backside with black spots that create the likeness of a smiling skull.



This spider seemed appropriately chosen to deliver an ADC. Another horny-backed orbweaver had spun its circular web smack in the middle of the picture window of

Grandpa's study. Grandpa had enjoyed the view out that window, as he sat working at his desk, *and* he passed away in that same study, where he lay in a hospital bed.

One of the best ADC's ever showed up four months after Neil died. It was a bright bandanna, and it arrived at a time when Dean and I were feeling particularly sad and discouraged. We had decided to take a walk through the woods at Goddard Park, a place that Neil frequented. Several women on horseback came riding towards us on the trail, and one woman mentioned a bandanna she had just seen along the way, suggesting we might want to retrieve it. It struck us as strange that she should mention the item.

The bandanna was hanging on a shrub next to the path. It was tie-died with rainbow colors, and it had a black print pattern of skulls, paisleys, clubs, spades, diamonds, and hearts. Without hesitating, Dean said, "Grateful Dead."

The graphic was in the style of the iconic hippie rock band we'd listened to in the 1960s and 1970s, during the rise of the anti-establishment subculture. The rainbow colors made me think of an illustration of the Jester, in Neil's storybook, leaving the hospital and running back to the kingdom, holding a long rainbow streamer in his hand. Back to the kingdom. This was clearly an ADC, thanking us for all the love and care we had given him, especially during the last year of his life. It made us smile.

When I got home, I did some research and discovered a relevant icon that was used on the cover The Grateful Dead Songbook. It was a skeleton dressed as a jester and holding a lute.



What I find really amazing is that just after Neil was diagnosed with cancer, an SLTP friend, Alexia, who is now a music therapist, stopped by to visit Neil and to teach him how to play a ukulele. The ukulele is a type of lute. Alexia taught him how to play the song “Radioactive” by Imagine Dragons.

“All systems go, the sun hasn't died
Deep in my bones, straight from inside
I'm waking up, I feel it in my bones
Enough to make my systems blow
Welcome to the new age, to the new age
Welcome to the new age, to the new age”

Although this ADC humor is dark, I can not help but laugh.
My son hasn't died; he has simply graduated from the school
of life.



Jingle bell wiffle ball

*This last story ties together the various themes that run through this book – perseverance and determination, reason and passion, how we relate to this world, life and death and ADC's. This is the story of the **Warped Chess Board**.*

THE WARPED CHESS BOARD

Seven days after Neil's passing, an acquaintance from his chess-playing days, Marie Ramos-Coccio, posted some photos from earlier days. She also wrote a few words:

"On behalf of the RI Chess community, I wish to share some wonderful memories of Neil Fachon. Neil competed in 62 National and local championships and achieved an expert rating of 2084. One of RI's youngest and strongest chess players. My sincerest sympathies to all who loved him. We will miss you Neil."

Marie's photos captured the intensity of Neil's passion and joy for the game of chess. Dean began teaching Neil chess when he was about three years old. At seven years of age, Neil started participating in after-school chess clubs. Then he progressed on to scholastic, local and regional tournaments.

A couple hours after Marie had posted the pictures, I received a message from my friend Cheryl White Swan Weeden, a Native American spiritual medium, who channels spirit through dreaming:

"Wendy! Sending lots of Love to you and your family. I am so sorry for your loss....I had a dream about Neil last night. He was riding a white horse. I just saw your post about Neil playing chess. I was led to this article about chess
http://www.enchantedmind.com/html/creativity/techniques/creative_chess.html

Cheryl's web link led me into the esoteric world of thought that Neil relished:

“For the creative mind, chess is more than a game of conquest, conflict, and competitive skill. Chess is a reflection of life creatively engaged.”

Further down the page I read:

“Chess mirrors our relationship with the outer world, and allows us to reflect upon our inner self as we warp and weave our way to victory.”

Ultimately I arrived at a deeply symbolic explanation of the game that alluded to the opposing forces of yin and yang:

“Examining the chessboard, we see that it has 64 squares of alternating color. One interpretation indicates that the white squares represent the path of the intellect and the black represents the devotional path of the heart. The chess pieces represent the forces of nature, light and dark, good and evil, opposing forces which permit the manifestation of all things material.

“Each piece represents a different position, power and possibility in the game of life. How you use each piece and the kinds of risks and gambits you are willing to engage is a great reflection of your approach to life. Let's examine each piece and it's potentials”.

Dean had once explained to me how the Knight is more powerful than the Queen. While the Queen can move any number of squares in any single and unobstructed direction – forward, backwards, sideways or diagonally, the Knight can move around pieces. The Knight is the one piece that truly warps and weaves its own way around the board. I skipped down the web page to read about the Knight.

“The Knight represents the awakening of the spiritual initiate acting in the world. It moves by leaps of intuition along the sides of a right triangle. It alternates between white and black squares with each move, therefore, engaging the head and heart in each action. Only a knight or a pawn can initiate the first move of the game. The Knight can make a move that even the Queen cannot make.”

Skipping further down the page I read:

“Some of the greatest games in history have been decided in the end game with only a single knight. Learning never to give up is a necessity in any problem-solving venture. If the true creative experience is to live an artful and successful life, then opening the mind to it's fullest extent would seem a necessary effort.

“Chess is an excellent opportunity to study yourself and how you relate the world. Are you cautious or fearless? Do you lead with your head or your heart?

Can you move between both at will? Can you see the whole and where it's leading or are you stuck in the isolation of the moment? Can you forge through to the very end without ever giving up?"

To lead with the head *and* the heart is to direct your passion with reason. Neil had developed that ability. After reading through the web page, I typed a response to Cheryl's message about her dream of Neil on the white horse:

"Dean placed a white knight piece, from Neil's tournament set, in Neil's gray thin hand as he lay in hospice during his last days. Check out the chess poster Neil had hanging in his room [I attached a photo of the poster], and notice the White Knight that made it up the ladder... gaining a full view of the dark side."

Eight chess tournament trophies still sit on a shelf in Neil's bedroom. Among them is the U2100 first place trophy for the 2011 Rhode Island State Chess Championship. On the opposite side of the room hangs a poster of *The Warped Chess Board*, a drawing by Swiss artist Sandro Del-Prete, who was inspired by the artist M.C. Escher. Del-Prete's curiously rendered artwork actively engages the observer.

The Warped Chess Board is an optical "delusion" that takes the viewer's eye from a 3-dimensional chess board in the lower half of the drawing up into a higher dimension in the upper half. Black pieces defend the upper side of the board, as one lone white knight completes his ascent up a ladder to attain a position in the upper realm. From there he can view the both

opposing sides of the board with complete clarity.

Behind the multi-dimensional chess board is a poster (a poster within a poster), depicting a cloud form, which is open to interpretation. At first glance it appears to be shaped like the profile of a person who is reaching out a hand to move a chess piece. At second glance, one might imagine the figure of God having a philosophical conversation with a small soul seated before him. The soul appears to be wearing a hoodie, and Neil loved wearing hoodies. At some point (I'm unable to recall when or why), Neil had draped a black ribbon across the top of the poster, hanging it over the thumb tacks that pinned the top corners of *The Warped Chess Board* to the wall. I find this really interesting now, because a black ribbon symbolizes mourning and remembrance.

Cheryl replied to my message:

“The dream makes more sense now after seeing your post and the explanation of the Knight in this article.”

I have often wondered: What if life is just a game? I recall a verse about the game of chess found in the Rubaiyat of Omar Khayyam. Khayyam was a famous 12th century Persian mathematician, astronomer, philosopher, and poet in the court of Eastern Iran. I messaged the verse to Cheryl.

“‘Tis all a Chequer-board of Nights and Days
Where Destiny with Men for Pieces plays:
Hither and thither moves, and mates, and slays,
And one by one back in the Closet lays.”

I messaged the verse to Cheryl, and she replied:

“So powerful a connection. The chess piece. As much as I do this work [dream work] I still feel amazed. I Thank Neil for sharing the vision with me. He is riding like the wind on a beautiful white horse.”

FINAL WORDS

Neil's best friend, Andrew Grady, who attended that first SLTP summer with Neil, shared the following reflections at Neil's memorial service:

“I urge you to focus on the good, not dwell on the bad. Neil would also want us to realize that when we come together anything is possible and that love defeats hate every time. I know that it seems unfair that someone like Neil has gone so soon. And it's true... But Neil would be the first to tell you all things happen for a reason, and he would try to find the good in it all. He has laid down the foundation on how not only to be happy in life, but how to spread it so that others may enjoy it too. It's now up to us to go forth and continue to do just that.

“Neil saw so many issues that he wanted to help fix, and he was interrupted in the process of determining which ones to tackle and how to go about it. He was at a point of divergence, and I will always wonder what path he would have chosen. As his illness progressed, and communication got tougher, there were so many times when Neil would say something to the effect of, “When I get better I'm going to have so much to share with everyone.” That all those feelings and ideas were locked inside of him is a tragedy for all of us. I think that if he had somehow made it through his illness he would have been unstoppable.

“I'm not telling you all this to emphasize the grief of Neil's loss, or the loss of the person he was becoming, but because I feel that it's our responsibility now to carry his torch. For me, that means living a more mindful life, engaging people around me, and thinking deeply and critically about big issues and solutions. For you it might mean something else. Just because Neil isn't here to do it anymore doesn't mean that it won't be done. And it doesn't mean that he won't, in some way, be the one doing it. Nothing will ever make his death okay, but I think that his absence will make me see his qualities more clearly in others, and appreciate them more for it.”

Neil's sister, Evie, shared these final words at the memorial service:

“While I'm up here, I wanted to share one more lesson that I learned over this past year. There are so many ways to show someone that you love them. As Neil's illness progressed, we slowly lost many of these ways. I showed him that I loved him by coming home and spending long days talking and keeping company. When it got more difficult to talk, our long conversations turned into shorter ones, to sentences, to single words. I showed him I loved him by decorating his room, by playing his favorite music, by cooking him food. He showed me his love by finally letting me win a few games, by greeting me every day with a hug and a smile. Slowly, we lost those things, too. When we couldn't say “I love you”

we would squeeze it. When squeezing got too hard we just held hands.

“Yet all of these things are just ways to show your love. When you lose them you don't lose the love. It doesn't go anywhere. If anything, when all of the love that you have is held in the warmth between two hands, you see it more clearly than ever. I can't hold Neil's hand anymore, but the love hasn't gone anywhere. Now I see it everywhere, and I will live my life as a way of showing it.

We arranged for a second memorial service in the Sacred Space of Ell Hall at Northeastern University. Nadine Aubrey, Ph.D., Dean of the College of Engineering at Northeastern University, honored Neil with the following remembrance:

“Neil was very involved in numerous student organizations while in high school, and actively participated in the Student Leadership Training Program. Upon arriving at Northeastern, he reaffirmed his interest in leadership through involvement with the Huntington Hall Council and the Institute of Industrial Engineers. Neil was a passionate community activist and volunteer: he took part in an Urban Heat Island Effect research opportunity, and explored his interests in the environment through studies in resource recovery and waste management as a participant in a Dialogue of Civilizations in Italy. He chronicled his experiences in an insightful and reflective blog entitled *Sardegna Adventures*.

“A Dean's List student who joined Northeastern with 36 Advanced Placement credits, Neil maintained a 3.9 GPA and was in the process of becoming a brother of the Eta Zeta Chapter of Beta Theta Pi when he was diagnosed with a rare form of pediatric cancer last spring. He faced his diagnosis with great bravery and grace, and remained eternally optimistic. Neil and his family aggressively sought out new ways to fight the disease and through valiant efforts, determination and a strong will, he fought the disease for many months until his passing on Sunday, February 19.

“Neil's friends remember him as a fighter. He faced insurmountable difficulties and did so with a smile. Neil's greatest strength was the positivity and genuine kindness that he brought with him wherever he went. He wrote in his application to Northeastern that after he began participating in student leadership training programs he 'discovered that the ability to be a leader and make a difference in the world was right inside me all along... I unearthed within myself a new level of kindness and caring, of optimism and positivity, of determination and perseverance...' these characteristics were put to the test as his illness progressed, but he never wavered.”

Among the speakers were four professors, Evie and Charles Cormier, who was Neil's big brother in Beta. Neil's Social Entrepreneurship professor screened a short video Neil had co-

produced about **Taking Action on Urban Agriculture**. Neil's friend Adam Bechtold read aloud the story of the Jester, and a capella group Distilled Harmony sang "Pompeii," with its poignant refrain: "How am I gonna be an optimist about this?" How am I gonna be an optimist about this? When we can ask ourselves this question in the face of any daunting situation, we open the door to great possibility.

On April 13, 2016, six weeks after his DIPG diagnosis, Neil met the amazing Dr. B, who greeted us with a warm smile and a twinkle in his eye. That same day Neil became the first patient to enroll in the Burzynski Clinic trial. Over the following five days, we drove Neil around Houston to complete his pretrial baseline medical tests. Trial protocol required Neil to take dexamethasone for five days before having baseline MRI scans taken, so we had plenty of time to get familiar with Houston, shop for groceries, and settle into our hotel suite, where we anticipated spending the next four weeks.

Within five days, Neil was approved to begin the experimental treatment. A catheter was surgically implanted in an artery beneath Neil's collar bone, and he was ready to initiate his daily routine of peptide infusions. The same day Neil began the therapy, however, Dr. B received an unsettling letter from the FDA, suspending the clinical trial that it had approved and listed as active on the government clinical trial website. The timing was uncanny.

Your IND is on full clinical hold and you may not enroll new adult or pediatric patients in any protocol under this IND. In addition, you may not resume

administration of ANP in any adult or pediatric patients previously treated. We note that there are no patients currently receiving ANP under this IND.

When we studied the full letter in detail, we found the FDA's explanation for suspending the trial unjustified and lacking in reason. We knew that the cancer industry was seriously big business - more profit-centered than patient-centered. We had heard stories of bullying inside the industry. We had read the story about a government raid of Dr. B's office and the removal of his files. We had listened to the story about the 20-day court trial charging Dr. B with 75 federal counts of mail fraud and violations of federal drug laws. The court trial resulted in the dismissal of the 34 counts of mail fraud; the jury was deadlocked in the other 41 counts, and failed to come to a verdict. Beyond this, the internet was loaded with articles blacklisting Dr. B.

Texas was a "Right to Try" state, meaning patients diagnosed with a terminal disease could try a treatment that has passed Phase I clinical trial testing. Neil was eligible Dr. B's Phase II trial, and, if we wanted to split hairs, Neil was too old to qualify as a pediatric patient in some trials and too young to qualify as an adult patient in others. He was ineligible, because he fell outside the age brackets, and through the crack in between. Since he had already signed the legal documents, accepted the risks and begun treatment, he asked to continue the therapy while Dr. B sought further clarification and justification in writing from the FDA.

During that same time, the doctor was preparing his defense for the continuance of another court trial - Texas vs. Dr. Burzynski - taking place May 4-13 in Austin. On May 3,

Dr. B received a second letter from the FDA, specifically disallowing him from treating Neil with the ANP protocol in his clinic. We managed to secure an opportunity to speak with the officials at the FDA responsible for this decision, and our conversation left us with the strong impression that the FDA was a bureaucracy devoid of empathy, out of touch with our reality, and perhaps beholden to big pharma entities.

The story that unfolded from this point until Neil's death is a long story filled with ambiguity, subterfuge, and cycles of hope and despair. I often felt as if we were caught in the middle of a game of cat and mouse. The FDA playing the cat and Dr. B. playing the fiercely clever little mouse. Dean likened the experience to a game of chess, with moves and counter moves. Neil and Dr. B were the white knights.

In the end, the great miracle for Neil was that he survived for almost an entire year without having undergone radiation, which was the **only** therapy approved by the FDA for DIPG. How he accomplished this, against great odds, is a story worth knowing, however, it is not my story to tell here. It is currently being written by Neil's father, for it is a difficult story that takes great strength and technical skill to write.

I often asked myself, "Why Neil? Why not me?" I would have traded places with him in a heartbeat. Losing Neil was terribly painful for me. After his death, the pain in my heart spread to other muscles deep beneath my skin. It moved slowly toward my left shoulder, up my neck, and down my arm. Overtime, the shoulder pain sharpened so that I could hardly sleep. Over a period of five months I lost the mobility and strength of my left

arm. My body was trying to tell me something.

I sought treatment through my primary care physician, a chiropractor, and an osteopath. As the problem grew, they all failed to diagnose the problem correctly. Their efforts at treating the issue were ineffective. Finally, I insisted on an MRI scan. The conclusion was a frozen shoulder. The osteopath referred me to an orthopedic surgeon, who recommended a cortisone shot and physical therapy. These remedies added to the pain, but only for a while.

Looking beyond the physical aspects of my disability, I read articles by intuitive therapists, explaining that frozen shoulder was associated with an instinctive drive to protect the heart from unbearable pain. I was stoically holding the grief deep within, unexpressed and unprocessed. I needed to work my way through the pain on multiple levels: physical, emotional, and spiritual.

My sister, Sandy, referred me to an energy healer and spiritual medium, Jacquelin. When I connected by phone, Jacquelin spoke about the part of me that had died along with Neil. Is that possible? She explained that I had a choice. If I wanted to move forward with my own life, I needed to resurrect the part of myself. There was really only one logical choice; I still had a husband, a daughter and others who rely on me. I had to figure out how to pull myself back together.

Jacquelin helped me start the deep spiritual work, and she urged me to write as part of this healing process. By combining the spiritual work with daily double doses of physical therapy, myofacial massage, and swimming pool therapy, I found myself on the slow, yet certain, road to reclaiming my well-being. Healing from the loss of a child is a lifelong journey, with many different pathways from which to

choose. We can dwell on paths of denial, sorrow, and regret or seek out paths of joy and renewed purpose. I knew, without a doubt, that Neil would want me to seek out the most positive pathways.

To my surprise and delight, Jacquelin channeled Neil's spirit with great clarity and on a deeply intimate level. In our second session, I listened intently, as she channeled Neil's excited rapid breathless run-on sentences. He had so much to convey, and he hardly completed expressing one thought before blending it into another, knowing I would understand, once I heard the words and gave them some thought.

Jacquelin recorded the session, and afterwards I took my time relistening, transcribing, and digesting the words. I tried my best to interpret and clarify the information, because I realized Neil's message was for others besides just me. So, for those who are prone to hopelessness, lost in grief, seeking meaning in their life, or simply interested in reading the insights of someone who has passed on from this life, I share some of Neil's words through the following unedited transcript:

“Mom, I still get the experience of this rapid acceleration of transformation in physical reality, because you're here. I fulfill that karma, and you're here fulfilling that, so I simultaneously get to fulfill both. As you fulfill this as a feminine on earth, where it [earth] was held subservient and went into this wounded patriarchy scenario construct and everything was shut down and made subservient, so they could take control of things and take destiny in a particular direction to the point of extinction, how amazing it is that you're living on earth and you've tempered yourself and you've gone to the degree you have

while all this is being tempered, so that now you can step in, in a really balanced, really altruistic way, of bringing a message out to humanity, but at supporting and uplifting the young people, the younger generations, because they're very disillusioned with this reality and they need to be reminded of the big picture and their role in it, and the preciousness of their lives... and that they [each] have certain talents and abilities in equation of their own self that is brilliant and set up in a way that nobody else has, and they are able to come into this fabric of existence to effect it by their very equation of their brilliant self, just like you, Mom.

“But many of them were not as fortunate as I was, Mom, as your son, to come into families with such awakened mothers, and so it wasn't mirrored back to them, and they have all this confusion why they're here, what they are to do, and so some are falling between the cracks and ending their lives earlier when that wasn't even meant to be, because they're feeling like it's hopeless here. Mom, when I passed, you went to the aspect of life that feels hopeless... you allowed yourself to experience that and let go of everything and say...

“I'm not going to do a damned thing. I'm going to embrace what this hopelessness is, because I can't jump past it and pretend it's okay. It's not okay. There is a side of life that is absolutely hopeless, and, God, you have to show up for us in that hopelessness, and I'm here in that hopelessness, wanting you to show up with me and for me, because humanity needs you to show up in that place of hopelessness now, because that seems to be running the show. That seems to be the all-pervasive power here, and we're not going

along with it anymore. We can't, please help me. Show me. Help me to experience the transcendence that we can [back] to life, from that place of hopelessness, because so much of the world is in that hopelessness. So, I'm here. I know what it feels like. I'm relating to them. It feels like 'Why do anything? It doesn't matter.' Why transcend when you take two steps and you're knocked back down. Or why birth a child into existence only to have to let go of them and not be able to see them fulfill their life? Why come here with all this brilliance and transcendence, and yet what controls this world wants to suppress it and rip it apart... and cover it and make evil appear like the way to go... and when does it change? When does it actually change? When do we get to see the results?'

“And so it's perfect, because in the extreme polarity, when it seems like we're already headed for extinction, [there's an] agreement to reemerge from your own divine authority, except that God is reminding you that you will never be alone... now imparting at an accelerated rate... many on earth are not from the original blueprint of God... message will reach those from the true organic source Mother Father God... moving into the vibration of love... God spark God power within them... restore... move through inertia to the other side of this suffering... even in helplessness, all humanity will be fulfilled in their destinies in this time of great change. God is present in all hearts, needs no intercession... Realm of Cause...”

Realm of Cause? I had never heard the term before. It provoked my curiosity. Did it refer to an actual place or a state of mind?

In this same session, Jacquelin read my astrological chart. I was born Ascendant in Capricorn with the Sun in Taurus. She told me that people born under this astrological alignment are preordained to learn hopelessness. These people are incarnated on Earth for the purpose of understanding the components of suffering, so that they can, in Jacquelin's words, "compost them into greater power, knowledge and understanding, and take this back into immortality as a result of their physical life experience."

Composting is an apt metaphor for the transformational process that works with the cycles of life and death here on Earth. Under the right conditions, weeds, dead leaves and dung can be transformed over time into rich soil and life giving abundance. Applying this metaphor, is it possible that hopelessness, pain, and suffering can be transformed into hope, love, and joy?

Jacquelin gave me the answer to my ultimate WHY: Why am I here? She said it was "to find and open the doorways that lead out of hopelessness, to learn how pain and suffering can contribute to transcendence and consciousness, and to help carve a path that leads back out of the darkness."

She told me that it was "agreed to have your son trade places with you and leave early, so that you could now impart this to humanity and to the young people we're losing on the earth, who are opting out of life earlier through drugs and suicide, because they lost their understanding of what they were here for... and yet we have your son who wanted to hang onto life at all cost." Is that possible?

After giving this much thought, I resolved to write and share this collection of stories about Neil's teen years, with the purpose of moving people's attention away from the

overwhelming negative energies have been dragging our planet down. To think, believe, see, and imagine with a positive and open mindset is more important than ever before.

To understand the nature of our physical reality, it is essential to understand the nature of energy itself. How does energy work? How does energy flow? How does the energy within oneself, and the components of that energy, emerge into creating our physical reality? Because in truth, we all have the power to give form to reality through the energy we create with our words, thoughts, affirmations, attitudes, and actions. While we may not have control over the distressing events that surround us, we do have a choice as to how we react to those events, energetically.

At our core, each of us is a divine spiritual being with an infinite source of creative energy, capable of thinking and doing in new ways. Back in May 2016, as Neil's handwriting was starting to be affected by the brain tumor, he scratched out the following words on a note pad: "In the news ppl want a cause, something to back and something to do. Get the right ppl in the right places, sit back and watch." Neil diverted both his thoughts, and his energy, away from his own negative circumstances toward the positive process of thinking about how to solve challenges much larger than his own. He also strived to help others achieve their greater potential, with the intent of seeing the collective good unfold.

If we focus on reacting positively to life's challenges, we *can* create a better outcomes. Sometimes the actual outcomes may fail to align with our expectations, hopes, and dreams. Yet even as some outcomes may disappoint us, it is important to remember that our positive intentions can still serve a higher purpose. I believe to some degree that this is because the souls

residing in the higher unseen realms are able to see further through time and space than any of us earthbound mortals and that they can help steer our energies. Our positive energy radiates outward beyond our knowing – cause and effect, the effect of an effect, and so on... We witness so little of how we actually affect the greater world around us... only as far as we can see. Neil would urge us to stay positive and never give up, because you never know just how much your actions may actually be helping to create a better world, even if it appears you may have failed.

I hope people enjoyed reading this collection of stories, written in Neil's memory. I certainly enjoyed writing them and am delighted to be able to share them. I hope people can draw some strength and wisdom from these stories, because as I have been writing them, humanity seems to be in the darkest place I have seen in my lifetime. I'm keeping my eyes open for angels, and I sense that everything is going to be okay in the end.

Most of us feel like bystanders living in the midst of a current reality that is stranger than fiction. We should be asking a lot more questions, and we should be digging deeper for answers.

I wonder what Neil is thinking as he looks upon this world-sized game board of challenges – a global pandemic, a highly experimental vaccine, allegations of voter fraud, internet censorship that negates debate, citizen surveillance, racial unrest, educational disparities, environmental degradation, and the list goes on. I remember our family of four, sitting around the table in our Houston hotel room, figuring out how to play the board game called Pandemic. It's a cooperative game, that requires everyone to work **together**.

“In the news ppl want a cause, something to back and something to do. Get the right ppl in the right places, sit back and watch.” My causes are environmental education and health. I have combined my gift for storytelling with walking to create the Story Walking Radio Hour. Walking is exercise *and* it helps me to see and know the actuality of my environment. Storytelling helps me to share what I have come to know in an engaging manner.

What I have come to know, as I have walked through life, is that cancer is a multi-billion dollar industry that generates enormous revenues with marginal benefits to most patients. Many families who have lost children to DIPG have created foundations to raise awareness, fund research and provide financial and emotional support to families with newly diagnosed children. For my part, I seek to illuminate and eliminate the environmental causes of cancer, which are largely industrial-based activities that exploit both natural resources and people... for profit.

My hope in sharing Neil's story and my radio podcasts is to bring people together into a caring community of listeners and activists. Positive change is possible, and we are all capable of solving causal problems, especially if we share what we come to know through our experiences – our stories. Find your cause, your gift and your path. Find others who share your passion. Keep the faith, shine your light into the world, and help to make it a better place for everyone. With love and gratitude!

ABOUT THE AUTHOR

Wendy Nadherny Fachon is an environmental journalist and educator. She hosts the **Story Walking Radio Hour** on the Dreamvisions 7 Radio Network, and she writes for Natural Awakenings Magazine's Boston/Rhode Island edition and **Dreamvisions 7 Radio Network's** *Sustainable Living News* platform. In addition, she researches, writes and co-teaches Nature Drawing curriculum for The Empowerment Factory.

If you enjoyed this book, please support Wendy's education initiatives online at www.patreon.com/storywalkingradio

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