



# **SAVE THE PROUTY GARDEN**

**AT BOSTON CHILDREN'S HOSPITAL**

**PATIENT & PARENT STORIES**

# THE GRECO'S STORY

It was July 12th, 2015, just 5 days before the 2 year anniversary of my son, Jason's, death. Just like last year and the many times in between, we planned to make a 4 hour drive from New York to visit an incredibly special place - the Prouty Garden at Boston Children's Hospital. It may seem odd to drive 4 hours just to visit a garden, but maybe the following will explain.

Boston Children's Hospital is such an extraordinary hospital for so many reasons. Mainly because it offers children some of the best care in the country and more often than not, it is the "last stop" for terminally ill babies and children. But in addition to the exceptional staff and state-of-the-art facility, BCH has this magnificent garden in the epicenter, or the "heart" if you will, of all its buildings. This garden is spectacular with beautiful bushes and trees, an open field with statues and a fountain, and many secluded areas in its shady corners. It is truly the "heart" of this hospital because it is visited by everyone; patients, families, staff and anyone in between. It is a magical place that offers a level of healing that cannot be found anywhere else. Trust me, I know.

My son, Jason spent 4 months at BCH. In February of 2013, he and his twin brother, Justin, were born 2 and 1/2 months early at a local hospital on Long Island in New York. Within 48 hours, Jason's condition started to rapidly decline due to a catheter that was misplaced in his body, puncturing his liver and causing him to go into liver failure. After a month of unsuccessful treatment elsewhere, we had Jason flown to Boston Children's Hospital.

During the 4 months Jason spent at BCH fighting for his life, I was there with him almost the entire time. The nurses would encourage me to leave the building to get some fresh air, but the only place I would allow myself to go was the Prouty Garden. I'm so grateful that I took those opportunities to spend time in such a beautiful place. I think I would have lost my mind listening to all the machines and monitors all day long.

Eventually, Jason's progress had hit a wall, and we knew it was the end. On his last night, the only request my husband and I had was to bring him to the garden. It was a challenge because Jason needed so much equipment, but the nurses and doctors made it happen for us. We were grateful. It was the only place he'd ever been, other than a hospital room. It was the only time he was ever able to feel fresh air. It was the only time he ever saw moonlight and heard crickets. It was the best night he ever had.

An hour after Jason's visit to the garden, he passed away in my arms. It was the most tragic moment my family will ever experience, but I have peace knowing that he was able to be in that garden, even if it was for just a brief time.

So now maybe it has become more clear as to why my family would drive 4 hours to visit a “garden.” It’s not just any old garden. It is a place that is so sacred and so special to my family and to many others as well. And even though we only get to go a couple of times a year, it has become a family tradition, in honor of Jason.

We have a “spot” we like to go to. The spot we took Jason to on the night he died. My husband and I usually reminisce about how incredible the staff was that night and how brave our older son was as he read a bedtime story to his twin baby brothers. We recall how beautiful Jason looked as the moonlight twinkled on his face and how the warm breeze messed with his hair. I try to take in some deep breaths as if I were reliving the evening and remember the last moments we were complete, as a family of five. Every emotion comes flooding back and I always have a good cry. Some may think this would be difficult for us, to go back there and relive the moments before our son died, but it’s quite the contrary. It brings us extreme peace. It allows us to remember him fully in the place where he had the best moment of his short life. It allows us to feel gratitude for the love and support he received that night from everyone who knew him. It allows us a chance to make Jason’s life more real to his brothers in a beautiful and meaningful way. Being there makes us feel closer to him because we never got a chance to bring him home.

Just a few weeks ago, on that Sunday, July 12, as I had mentioned, my family had returned to the garden for our Anniversary visit. When we got there, we walked into a hospital that used to feel so familiar, but now looked completely different. When we went to the front desk to check in, we were told we couldn’t go into the garden. We no longer had a patient there and the garden was not open to the public. And even after I explained why we wanted to go, we were still refused access.

We felt devastated and defeated on so many levels. For one, we knew that there was a chance that the garden would be gone soon. Would we ever get to be in that comforting place again? It was so difficult to know that the most sacred place for us was just a few short corridors away, and we couldn’t get to it. And that just behind the people at the front desk, who were given “heartless directives,” were the most caring and compassionate medical teams we’d ever met. People who were such an important part of our lives during such a crucial time.

I couldn’t understand the logic. We only wanted to be there for a short while. And now, not only did we have to say goodbye to our son, we have to say goodbye to the only place that brings us comfort...without any warning. And in addition to the possible destruction of this beautiful place of healing, the people who need it the most are not able to embrace it while it still actually exists.

I’m really not sure who is making these decisions about the garden, but it is clear to me that they just don’t get it. They are clearly not seeing all the patients enjoying the fresh air each day. They are clearly not noticing the staff using the garden to escape their stressful shifts for a brief break. They are definitely not present when families choose to bring their child to the garden to spend their last moments together. I hope that one day soon, they begin to see all of this more clearly, because not only is my heart breaking, the hospital’s heart is too.

# LOVE AND HOPE FOREVER BY ESTHER MORALES

IN MEMORY OF FERNANDO 1994-2015

“It is so nice to breath the air outside.” Those were Fernando’s words in an entrance from his diary dated November 2011. He was referring to his first visit to the Prouty Garden at Boston Children’s Hospital. It was already dark when the nurse was able to accompany him to the garden. The next day he was able to go in the daytime and it was



a tremendous treat. He had spent many days in the hospital room suffering from side effects due to chemotherapy and radiation to treat his cancer. Fernando was 16 years old when he was diagnosed with Ewing Sarcoma in March 2011. He fought together with doctors, nurses, and other staff at Dana-Farber Cancer Institute and Boston Children’s Hospital for almost four years. He died January 16, 2015.

When Fernando had to spend days in the hospital for complications from his treatment the nurses introduced him to the Prouty Garden. What a contrast from the maze of hallways inside the hospital and the room that felt to him like a prison. When the glass door opens you see the magnificent tree, the fountain, the flowers, grass areas with paths to walk, places to seat inside nature. It is like a beautiful dream in the middle of chaos. We were in awe every time we entered the healing peace of the garden. To Fernando and everyone in his family the Prouty

Garden was an oasis. Walking around when we could, sitting with visitors, or alone, and taking pictures were a delight in the middle of the horrific battle we had to endure.

In 2014 after his second relapse Fernando had a few stays in the newly remodeled Oncology floor. We were able to use the small pocket garden in the floor. I don't want to be ungrateful, but even though it is better than the hospital room, the small garden did not have the same effect of peace and healing that nature can bring in the Prouty Garden.

As a mother and citizen I am heartbroken at the thought of Boston Children's Hospital losing this healing garden, which is an irreplaceable gem. My son is already gone, but how about the other children, teenagers and families that need this garden to help them go through their battles. I also feel sad for the staff that now can use this peaceful space to decompress during their breaks from a stressful job. I believe that having this space improves the quality of care they provide.

My son Fernando loved nature as many young people do. It was very therapeutic for him to spend time in the Prouty Garden. I can attest from my experience that there is no comparison between the Prouty Garden and the small pocket garden/play space areas. They have a different purpose. Those areas are good but can never give the same healing and peaceful effect that the Prouty Garden can give to the staff, families and patients at Boston Children's Hospital.

# DAVID'S STORY

BY ELIZABETH RICHTER

When my little brother, David, was three years old, he was diagnosed with a brain tumor (craniopharyngioma). We were living in Princeton, NJ at the time, but my parents decided to bring David to the Children's Hospital in Boston for surgery by Dr. John Shillito. For the next ten years, David and my family made many trips to Boston because David had multiple surgeries and many admissions to Children's Hospital.

David, pictured with his mother



*David, pictured with his mother.*

Unfortunately, in those days, children were not allowed to visit on the ward, so the only time we saw David during his treatment at the hospital was when my parents placed him in one of those wooden carts and rolled him into the Prouty Garden. From there we would walk around together and simply enjoy the birds, the chipmunks, and the squirrels. We would marvel at the fountain and admire the trees and the bushes and the grass. I think we all had a sense of the beauty of those transitory moments together and tried to appreciate them to the fullest.

On February 1, 1973, just before his 13th birthday, David died unexpectedly in his sleep at home in Princeton, NJ. My parents brought his body back to Children's Hospital so that the doctors could learn more about David's disease by performing an autopsy. Dr. Shillito met my parents at Children's Hospital and personally lifted David's body into his arms and carried it into the hospital.

My parents decided to have David's body cremated. My brother flew in from California, and my sister came up from New York. We met together as a family in Boston, and concluded that we wanted David's ashes scattered in the Prouty Garden where he had spent so many happy times with his family.

Since my brother's death, my parents made it a yearly tradition to return to the Prouty Garden to remember my brother until their deaths, my father in 2009 and my mother in 2014. I lived in Boston for 12 years and always made sure I joined them in these visits.

Once I moved to Connecticut where I live now, I still always try to make it back to the Prouty Garden at least once a year, as do my brother and sister. Boston Children's Hospital is always a home for me. And the Prouty Garden is one of my most sacred places, not only for me, but for every member of my family who remembers David's courage and his capacity for joy, and his love of the little things that made and continue to make the Prouty Garden so special.

# QUESTIONING THE LOGIC OF DESTROYING THE PROUTY

BY SARA CURTIS

My experience at the Comfort Ability Clinic was not “fun.” The Clinic was located on the ground floor library close to the Prouty Garden. I started the day in a crowded conference room with nine other children with chronic pain issues and their parents. I remember sitting in the dry, hot room with my father and looking out across a fresh-cut lawn, spotted with trees that had, in the peak of autumn, flamboyantly displayed their vibrant colors, and wondering how such a place could exist in the middle of a hospital that needs all the space it could get. Flash forward to April 28th, when Charles Weinstein, director of real estate for the Children’s Hospital Boston, stood in front of the Landmark Commissioned and argued “in order to save the lives of more children” the Prouty Garden would have to be destroyed. Then I learned that such a place could not exist peacefully, and without conflict, in a constantly developing world. I have no rebuttal to Weinstein. He is correct- the new unit that will be built on the current Prouty Garden will only serve to save more lives- the goal of every hospital. Now that the petition put forward to save the Prouty Garden was denied, this construction will most likely commence.

However, I would like to bring another impending issue to rise: the absolute necessity of these children and their parents, confined to a world of medicine, machines, and harsh reality, to have the contrast of peace, nature, and serenity that the garden offers. Now, the hospital has argued for some time that there is alternate green space available throughout the grounds, and I would like to, through images and descriptions of these places, prove that these areas are not viable as replacements for the necessities the Prouty Garden offers. The first area we will look at is the outdoor playground located outside the specimen-sampling wing. This playground, though equipped with the typical necessities for a child to have a good time (a slide, things to climb etc...), the atmosphere created by the surrounding rattle of exhaust vents, total lack of greenery, and the harsh asphalt ground, by no means replaces what will be lost with the demolition of the Prouty Garden.

The other “park” of notable size is located on Jimmy Fund Park, outside a freight loading dock.

I cannot even begin to explain how outraged I was when I visited Mandell Park, however I will attempt to paint an image with my words. The noise was deafening. Trucks and cars rumbled past, their vocalizations made tenfold louder by the high concrete building-sides of the surrounding area. The Garden itself is a patch of concrete, where upon my arrival, three loitering adults promptly snuffed out their cigarettes. In front of the Park sits a 16 nozzle industrial fire hydrant, marring the already depressing attempt to bring greenery to the area. There was not a child in sight. There were no attractions for the children either, nothing noteworthy at all was visible in the garden. I believe my thoughts at the time were “the only likely thing to happen here is a child getting hit by a car.”

Now that the Prouty Garden is being demolished, there is no alternative place for meditation and connection with nature to be plausible. If these parks described above are what the hospital considers acceptable as replacements for the Prouty garden, then I pity and child or family who visits the hospital in the future. Being only sixteen years old, I have yet to learn much of the professional issues the hospital faces, yet I can speak on the side of humanity, and on the side of the patients the hospital affected (many of whom are too sick to speak up themselves). I ask the public, shouldn't the role of a “public” hospital be to benefit said public in every way possible? If we accept Weinstein's logic, that for the public good this new wing must be built, then we also must apply this argument to the necessity of a new garden of equal value to the Prouty, an issue that has not yet been addressed by the hospital. The visions of acceptable greenspace the Hospital has put forward since the Prouty do not reassure that this will be achieved.

# JUNIPER'S STORY

BY SHELLEY SENAI

I am adding my voice to the thousands of others who have urged you to consider saving the Prouty Garden. Here's my story.

Let me first state that I have nothing but the utmost respect and gratitude for Boston Children's Hospital. Your fine neonatal surgeons, in particular Dr. Thomas Hamilton, and skilled nursing units, in particular the nurses on 10 East, 10 South, and in the NICU, without a doubt saved my daughter Juniper's life last year. Not to mention the excellent outpatient team associated with the Center for Advanced Intestinal Rehabilitation (CAIR).

Juniper was born with gastroschisis at Beth Israel Deaconess Medical Center. Her bowels were protruding from her abdomen through a small perforation near her belly button. Immediately following her birth, she was taken via ambulance into the OR at Children's where Dr. Hamilton skillfully replaced her bowels into her abdomen and made her whole once again.

After a brief stay in your NICU, she was transferred to 10 East where we spent the first seven weeks of her life huddled together as a new family of three, trying to make sense of life with a newborn in a hospital setting. Our baby's bowels were broken. She would need to go back into the operating room to repair two blockages, once her bowels had healed from the trauma of exposure to amniotic fluid and air. In the meantime, she was being fed through an IV in her chest, fully dependent on Total Parenteral Nutrition (TPN).

These weeks leading up to her surgery were full of anxiety and despair for me as new mother. I didn't know if my baby would live and not just live, but thrive. I wanted nothing more than to free her from the tubes and lines she was attached to and hold her in safety forever. But we needed those tubes and lines. We needed to be there at the hospital. And so, we tried to make a life for ourselves there. We got to know our nurses. We had a routine. My husband would go to work in the morning, and Juniper and I would take long walks around and around the 10th floor, me wheeling her IV pole alongside us.

In the evenings, my husband would come “home” from work and we would go to the garden. Always, every night, to the garden. Yes she was still attached to things, but the fresh air, the quiet splash of the fountain, the presence of others socializing, eating, playing games. It felt like life. Real life. Not fluorescent, sanitized hospital life.

In the garden, we took our first outing as a family. Juniper’s first newborn photos we snapped with our phones on the grass, us lying happily next to her. In the garden, she felt her first sunshine, her first breeze, her first grass. And we felt normal, like a family. Not a family in crisis.

Eventually, Juniper had her second surgery to repair her blockages and then we spent another six weeks rehabilitating them to the point where the doctors felt comfortable releasing us to go home. All told, we spend 101 days living at your hospital during the summer of 2013 and I can’t think of a day that we didn’t spend in the garden, unless it was raining. On the weekends, we’d take food, sketchbooks, novels, and Juniper of course, and we’d set up a picnic. We met other parents there and got a feel for the community that was happening in this big hospital around us. We had garden regulars that we saw grow and heal, other families who depended on the garden to entertain the young siblings of children receiving treatment. We witnessed some patients for whom it was an entire production of nurses and family members just to get them to the garden, and they couldn’t stop smiling once they were there.

Since I learned that the garden might be demolished, I have been asking myself: “What will families like us do, without the Prouty Garden?” I’m talking about the people who make your hospital home for months, sometimes years. Where will they go to feel normal? Will they eat their dinner in the same hospital room they’ve been pent up in all day? Will their baby feel air for the first time in some small shaded courtyard with artificial bird sounds? Where will they go for a game of soccer or baseball? Will they be able to meet other families in the bustle of the basement cafeteria? How will they survive?

Because I’m not sure that we could have. And I don’t think they should have to just “survive.”

I respect that the hospital needs to evolve to continue to provide its state-of-the-art medical care to children of the future. But at what cost? There is only so much space on that property in Longwood. There has to be a better solution.

# A FATHER'S STORY

SHARED BY PATRICK SWANSON ON SAVE PROUTY'S BLOG

My daughter is also wheelchair bound and regularly visits the Garden between clinical visits and when she is inpatient. She cannot speak and does not often express herself but when she is in the Garden, her whole countenance changes. It is as if she knows that is the one place where she knows she won't be intubated, cathed, get bipap, have her port accessed or any of all the other painful things that happen to her. She just likes to look up at the big Dawn Redwood and smile. Prouty is the only place in that whole area where she can hear birds sing or children play without the noise of traffic or the constant din from all the stuff on the floors or clinics.

For her, the Garden provides a sensory experience that can only be had in nature, and it is very therapeutic. Prouty has its own little ecosystem. She can see squirrels, rabbits and birds as well as the variety of trees, flowers and bushes; enjoy the wind and sunlight on her face, and she can be feel peaceful and safe.

There is a tangible feeling of goodwill and harmony in the Garden; how many thousands have enjoyed and added to that sense of peace. Some children have drawn their last breath in the shadow of the redwood, and the ashes of at least one child nourish it and all the other trees, grass, and flowers. Those children especially, and all the other kids who never made it out of Children's, consecrate that Garden and make it holy. Maybe the holiest place in Boston.

Prouty Garden cannot be replaced by some trendy rooftop design cooked up in an office where there are no sick kids. Sacrificing the Garden so some administrators in an ivory tower who will be gone in a few years can build themselves a legacy is a detestable travesty. Children's Hospital has a powerful and unique legacy as a place of wellness. At the core of the hospital's legacy is the Garden. It is disingenuous and hypocritical to say, "Until Every Child is Well" or whatever their slogan is, and destroy a primary source of wellness that has been there for decades.

There is no hospital anywhere quite like Children's, and the Heart and Soul of it is Prouty Garden.

# BELA'S STORY

BY KATE, HER MOTHER

I am supporting your work, as I came to know the Prouty Garden last September when my daughter, Bela, was admitted for what turned out to be a very treatable case of Osteomyelitis (infection in the bone of her leg). However, she was inpatient for six days, and there was a period of time when she was first admitted, when the doctors were ruling out bone cancer. Needless to say, it was a stressful time for Bela, who was only four at the time, as well as for our whole family. I heard about the garden from the “play ladies” and got down there as soon as possible. What a treasure, I thought, and when can I get Bela down here?!!

As soon as she was able to walk, we loaded up her tiny walker with some stuffed animal friends, unhooked the IV, and headed down to the garden. She was absolutely thrilled...to watch the bunnies, see other kids and families, introduce her stuffed animal friends to the different garden statues, laugh and be out of the hospital setting. At one point, we took a seat in the small garden structure in the corner by the giant redwood...watched the fire flies and used the dark night and the flashlight in my phone to have a shadow puppet show on the garden wall. Bela laughed, our hearts filled with joy and relief to have this special moment.

Having grown up in Center City Philadelphia, but always having a love of gardens and open spaces, I was amazed to find this treasure. Am I correct in saying no other major children's hospital in the US has such a space for their staff and patients? My father was an architect and historian, so I was also impressed that the garden had been designed by Olmsted Brothers' firm.

So, when I heard there were plans to remove the garden for more hospital buildings...I was beyond shocked and began paying attention to your group's efforts.

How could such a world class institution not realize their duty to maintain such a treasure, and to abide by the terms of the Trust created with the Prouty family? I have been actively involved in my family's small charitable

foundation in Cleveland, Ohio and worked in the non-profit world for most of my professional life....how could the Children's Hospital's Board of Directors break the terms of this trust? And how could the Landmark commission not identify this as a TRUE Boston Landmark, especially in light of it's designers place in Boston history?

Your group absolutely has our family's full support and I definitely plan to donate to your efforts and make myself available for any events I can attend. Although I was not able to be there for the rally due to work responsibilities, I was with you in spirit and in solidarity!

# ROSA'S STORY

BY ROSA LINDAHL

I walk a lot these nights, in the quiet and gentle night of Southeast Florida, with breezes usually blowing, late enough to be still and quiet for most of the way. I feel like I am preparing, walking my way toward Gloucester and the silent retreat I will make right after New Year's. I'm going to FedEx my bag to the retreat center so that I can travel relatively unencumbered. I'll get into Boston in the middle of the morning and I don't have to be at Eastern Point until 4 or 5. In that in-between time, in that thin space, I am going on a small pilgrimage. That day it will be seven months since my mom's death and I will be in a city that redefined embodiment for me in profound ways.

In 1961, when I was 18 months old, I was diagnosed with a dislocated hip. The story of what followed is long and tedious, but it revolves around numerous surgeries and stays at Boston Children's Hospital. Dr. William T. Green was a world-famous pediatric orthopedic surgeon who called me "Mystic Rosa" and would tell me, a small and scared baby girl, that if he could, he'd buy me emeralds for my ears (most baby girls get their ears pierced at birth in Colombia, and all my baby pictures show me with little pearl earrings. That seemed to amuse Dr. Green immensely). He made it possible for me to walk, performed a minor miracle after a doctor in Colombia got sloppy with my post-op care and caused the bone in my femur to start dying. He was also the person who had to tell my mom, not yet thirty, that while he thought he'd salvaged my hip, I would need to be in a hip-spike cast, chest to toe, for at least 4 years and he could not guarantee that I would ever walk.

Before that reconstructive surgery, I had pins in my thigh bone, that were screwed tighter every day to force the bone to grow. In the sixties and seventies, parents at the hospital were considered a nuisance so my mother had to leave at 6 every day. I don't remember the pain, though I understand it was intense. I do remember the fear and desolation every day, when my mom got ready to leave.

I also remember the ritual that made such an unbearable moment of daily abandonment bearable. My mom would get me on a stretcher and we'd go down to the garden of the hospital. The garden was surrounded on all sides by the buildings of the hospital, and it was quite large, at least to a child's eyes. All along the pathway around it, there were sculptures of animals, a bunny, a squirrel, a fox, a deer and a frog in fountain. One of the sculptures was a little boy, whom we named Hans, after my brother. Each evening, my mother would wheel me past them all and together we would say, "hasta mañana" to each one, saying good night to Hans last. When I

was at Children's in 1968 for my last stay, we went back to that routine and I have never forgotten those walks, the grace and beauty, the way my mom tried to give me what comfort she could, allowing me to feast my eyes on the garden, even when she couldn't hold me close because of the cast.

So on January 5th, in the dead of winter, I am going to go back and visit that garden. I am debating whether or not to ask to be allowed to go back up to the Orthopedic surgery unit. My memories of that particular space are still scary—I was there when iron lungs were still in use; the little girl next to me the last time I was there, Amy Schultz, was in one. I was terrified of the sounds it made and the isolation it represented. But I will get to walk through that garden, not get wheeled around it on a stretcher. I am walking not in orthopedic shoes, like the ones I despised all the years when I was growing up, but in regular people shoes. I won't be limping. My hip replacement surgery took care of that. Last night when I walked at a fast clip for over an hour and a half, I marveled at the strength of my legs and the absence of pain.

I am going to that garden to say another thank you to my mom, to Dr. Green, to Miss Cornell who did my physiotherapy in 1968, while her husband fought in Vietnam. I am making that pilgrimage deeply mindful that in this season, the Church insists to itself and to people like me, that redemption is incarnate; redemption extends not just to mind and spirit but to flesh and bone and body as well. I'm going back to that garden to thank God for the body I was given and the body I have now.