



Remembering Amy

A Mother's desire to help.

This is the story of a child who was like any other child, with just one exception. Amy Foose had Progeria. Amy's life may have been short, but the spirit of this special young girl touched the hearts of everyone she met. Her story reminds us that children with Progeria have the same hopes and dreams as all children have.

We invite you to meet Amy. Your heart will be touched by her spirit as you hear the fond memories of her loving mother, devoted best friend and favorite teacher. This is the story of a child – a child with Progeria.



*Amy Foose
September 12, 1969 - December 19, 1985*



Amy was born on September 12, 1969 and her arrival brought happiness and joy to our family. From the moment she came home from the hospital she was the apple of her siblings' eyes. Maybe it was because she was the youngest – maybe it was her sunny personality – maybe it was the fact that we all knew she was special, even before we realized exactly how truly "special" she would end up being. The youngest of four children, Amy weighed in at 5 lbs 9 oz when she was born and measured 19 inches from the top of her head to the tips of her toes. With a head full of shocking red hair, she was a doll and

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Letters from Friends



Being Amy's friend meant that some of our days together were truly remarkable. More often, it was just the ordinary routine of teens hanging out. We listened to music, spent time shopping, watched our favorite soap operas, and laughed mightily over the silliest inside jokes. But what I remember most about our relationship is simply Amy being there for me – she really knew what friendship was

all about. Whatever it was that we were doing, Amy was able to easily live in the present and make the most out of each and every situation.

It may sound strange, my remembering Amy as always being there for me. It seems as though it should have been the other way around and that I was supposed to be there to support her. In my mind, however, Amy was not someone to be taken care of or pitied. First and foremost, she was always my friend. As we used to refer to each other, she was my BFF (best friend forever) and she was great company too because she knew how to have a good time. Oh, what a laugh she had! The sound of her laughter is still with me today.

Attending music concerts with Amy were always exciting, too. Concertgoers and performers alike seemed to be drawn to her bubbly personality and she made the most of the unique opportunities she encountered. She often met famous musicians and celebrities like Boy



George, John Stamos, or the Beach Boys, and they chatted her up like she was an old friend. Like any normal teenager, you could tell from one look at her beaming face, she loved it! And I loved tagging along for another roller coaster ride with my best pal.

We never spent a moment dwelling on what could or could not be done for Amy. Not once did I ever hear her complain, "Why me?" or whine about things that simply wouldn't change. In retrospect, this is truly amazing. I am not sure that I would have been so hopeful and happy if I had faced the same challenges and physical discomforts that she did. To me, this is the most baffling part of Progeria. The very gene that takes so much away, also bestows amazing gifts like the joy of life, a great sense of humor, and unwavering optimism.

I am very hopeful that the researchers working with The Progeria Research Foundation will find a way to allow children with the Progeria gene to live long, healthy lives. And that one soon they will find the cure that will give these wonderful children plenty of time to share their special gifts with their families and friends.

In memory of Amy, I ask that you please show your support for PRF by making your generous contribution today.

Judy Renehan-Rouse
"Best Friend Forever"

I never considered Amy to be just a student. We clicked from the moment we met, when I first saw her from a distance, as she and her Mom were walking through the corridor of Goleta Valley Jr. High School. Little did I know that my life and that of my family would be forever changed.



Our relationship began as teacher and student. I was trying to help her with her spelling and learning her multiplication tables. We quickly became one of friends and it was impossible not to love her. She was so much more to me – like a soul sister, or as she and I would say, "My little angel."

Sometimes I would put her on my shoulders – together we seemed to become one person – and she would be the perfect height to see directly in the windows of the school classrooms. Like any teenage girl, she had a "crush" on a certain young man and we would walk past the room where he was studying. We would always stop at the window for a moment and if he happened to be looking out at the time, of course he would see her peeking back in at him. One of the few times I ever recall Amy becoming totally embarrassed!



Amy is part of our family and her family will always be connected to ours. When I was pregnant with my first daughter, Amy was always there for me and I was thrilled when she agreed to be my daughter's

Godmother. I had always planned to name my first girl Kristin, but once Amy came into my life, I knew my baby would be named after her. And I prayed that my new daughter would have the same love, warmth, compassion and joy in life that Amy did.

Amy's life had purpose and meaning and I feel so privileged and honored to have been close to her and to remain a dear friend of her family. I believe that the research The Progeria Research Foundation is doing will not only find a cure for Progeria, but will also find answers for some of the other diseases that affect us all as we get older.

Please be generous in your support of The Progeria Research Foundation, so that they may give hope to the children and families now living with this disease.

Patrice Botto
Former Teacher and Forever Friend



On December 19 1985, Amy attended her God-daughter Amy's Christmas pageant. Later that night, she suffered a fatal heart attack, at the age of 16.

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most of the time that is how her brother and sisters treated her...like their own little doll.

When Amy was about ten months an unexplained skin condition resulted in the first of many visits to many doctors, and with every examination and test the news grew worse –

mainly because there were never any clear answers to what was wrong. Time passed and still we hadn't solved the mystery of, "What is wrong with our daughter?" Progeria was virtually unknown within the medical community and although the experts were doing their best to give us a firm diagnosis, they simply couldn't tell us anything that was certain. Finally, in 1973,



after years of searching and worrying, we got the answer we were looking for when a doctor in Santa Barbara sent us to Harbor General Hospital in Torrance, CA. Through the hospital we later met Dr. Ted Brown, who at the time was one of the few doctors in the United States that was studying Hutchinson-Gilford Progeria Syndrome. When he heard of Amy's condition he contacted us and it was then that we finally knew what the future would hold for our daughter.

We immediately decided that Amy would have as normal and happy a life as possible – that she would be encouraged to explore her talents and would have our support as she pursued her dreams. We also chose to protect Amy from the reality of Progeria and we never discussed her condition with her, how the disease would progress and the fact that it was a condition for which there was no cure. And we didn't want anyone else to share this information with her either. Out of their love for Amy our wishes were always respected by family, friends, community, and her teachers. I still remember the day I received a phone call from her junior high school teacher, alerting me to the fact that they had discarded every issue of the week's Weekly Reader magazine because it contained an article that mentioned Progeria – they wanted to protect Amy as much as we did.

One of the hardest decisions I ever had to make came when we took Amy to a reunion of children with Progeria that was being

held near our hometown. This seemed like a perfect chance for her spend time with kids who were living with Progeria, young people that were just like her. She had a wonderful time, but when she asked to join the group for a day trip to Disneyland I wouldn't let her go. I was concerned about the chance that this extended contact might open the door for Amy to learn more about Progeria – and find out that her life would be cut short. She was such a happy child that I couldn't take the risk that learning the truth might shatter her happiness.

Amy never really saw herself as all that different from the rest of the world and I believe that this outlook allowed her to grab onto life and live it like any other child. All things were possible to Amy and in her mind, there was nothing that was out of her reach. She never passed up the chance to join the competition to become a cheerleader for her high school – even though she was never selected. Rather than becoming frustrated and choosing to give up, Amy would simply meet the challenge with her characteristic optimism, "Well, maybe I'm NOT tall, but I AM good!" Following



her last audition for the squad, they gave her the job of Mascot for the Junior Varsity team. Amy also tried out for Usherettes, a group of 60 junior and senior girls, and I remember the night she sat by the phone anxiously awaiting the phone call that had been promised to come by 9:00 pm – the one that would alert the winners of their selection as a new Usherette. As it grew late, Amy finally began to realize that her phone wasn't going to ring with the good news that she so badly wanted to hear. Just as she was about to give up hope, the doorbell rang and within moments our living room was filled with the all of the Usherettes! They had wanted to come together as a group to personally tell Amy that she had been chosen to join them – an undeniable

reminder that the world has a way of rewarding those who persevere.

Many people have asked me if children were cruel in their treatment of Amy, and I quickly answer that it was her friends and classmates that really embraced and accepted



*"I ask that you join me
by making a generous gift to
The Progeria Research Foundation."*

Terry Foose



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Amy as just another "one of the kids." It was obvious to them that she was different in one, very noticeable way – but they constantly showed her that this difference didn't mean very much to them. At school, Amy was popular and well liked by just about everybody and she was always involved in a long list of activities. She was a member of the Usherettes, elected to the Homecoming Court, a valuable addition to the school's yearbook staff and although not the best student, she always did her best. Amy also loved to dance and she never missed an opportunity to join her friends at the formal dances that mean so much to all teenage girls. And when Amy made her appearance, it was usually in the company of some of the most handsome young men.

It was through a friend of Amy's sister that she met the love of her young life, actor John Stamos. John was so dear to Amy – he called her and wrote to her and his friendship brought her great happiness. She made John a teddy bear and a year after Amy passed away, we were at his home visiting and he wanted me to see he still kept the bear in his bedroom. In their own personal ways, all of these special people made sure that Amy felt special, too.



The story of Amy's life is one of love and happiness but because there is no cure for Progeria this story also has a sad ending. On December 19, 1985 Amy died of a heart attack – at the age of 16. She was 37 inches tall and weighed just 26 pounds. Physical problems had been happening more frequently. One night after some major heart pains Amy asked me if she was going to die. I told her, "We're all going to die. Only God knows when." I don't know if that was the answer she needed but at the time that was what I felt in my heart.

When Amy was diagnosed with Progeria in 1973, there was no Progeria Research Foundation to turn to for answers. Back then, so little research had been done on the disease that most family physicians had never even heard of it. There was no test available that could give parents a definite diagnosis to confirm that their child was suffering from this rare and fatal disease. And there were no recommended treatments available that could improve the quality of life for children who had Progeria.

When I learned that The Progeria Research Foundation had been created and that within four years the gene that causes Progeria had been discovered, I knew that I had to support this important work. PRF has taken the first step in finding a cure and their research may very well shed new light on something that affects us all – the diseases of aging. I give to The Progeria Research Foundation in memory of Amy, who was so dear to us, and because I want to help PRF find a cure that will come in time for the children who are now living with this disease. I ask that you join me by making a generous gift to The Progeria Research Foundation.

*Terry Foose,
Amy's Mother*

"I give to The Progeria Research Foundation in memory of Amy, who was so dear to us, and because I want to help PRF find a cure that will come in time for the children who are now living with this disease."



The Progeria Research Foundation was established to find the cure for Progeria, so that children like Amy can look forward to long and healthy lives, and be given the chance to realize their hopes and dreams.

Today, **PRF** continues to be the driving force worldwide in Progeria Research and our agenda for 2005 reflects that leadership:

- Funding more research grants
- Sponsoring an international conference of Progeria researchers
- Conducting a Natural History Study of children with Progeria that will lead the way to clinical trials

At The Progeria Research Foundation, we believe that a cure for Progeria will be found. We realize that our accomplishments so far have been made possible by the contributions of our donors and friends. And we know that our future success will depend upon the continued support of people like you.

As you give this holiday season, we ask that you remember The Progeria Research Foundation and the children with Progeria – children just like Amy.

