

Embracing the Mission

In memory of Helen Chase Walsh

This is the story of Helen Walsh, her life with her young family, and her valiant struggle with a deadly, unknown disease. Yet, it is just the beginning of the story of how the Walsh family went on to courageously face Alpha-1 Antitrypsin Deficiency, defy the odds, and fight for a cure.

Arlington Massachusetts, a suburb of Cambridge, in the early 1950's.

In the Dutch Colonial home on Cheviot Street, life was very good. Robin Hood Road circled the neighborhood, with its beautiful lakes and woods, and Cheviot Street cut through the middle. There were about twenty families living in the valley. The families were more like family to each other than mere neighbors. Instead of the kids calling the parents of friends, “Mr. or Mrs. such and such...” it was more like “Uncle or Aunt.” Fred Walsh, who lived there as a child, says simply, “It was idyllic.”

Fred was one of four children, the younger – and quieter one – of twin boys, in the Walsh family. His mom, Helen, a former high school home economics teacher, was married to Jack, a popular college football coach and college scout. The two had met years before while teaching at the same high school. Everybody loved Jack, gregarious, positive and generous. And everybody loved Helen.

Her other son, Fred's twin brother John, recalls, “Everybody could count on Helen to help with sewing the hem of a dress, or whatever. She'd help anybody. We kids could always bring friends home, and they would be welcome. It wasn't unusual for there to be twenty kids at our house for lunch. Whatever it was, mom was the ‘go to’ person—just an enormous strength. She was everybody's friend.”

Fred, remembers, “She had a lovely singing voice. We would do supper dishes together and she'd sing, “The Isle of Capri.”

Years earlier, already the mother of three-year old Susan, Helen had a difficult pregnancy and didn't know until the last minute that she would give birth to twin boys, premature and fraternal. John and Fred Walsh were born in Boston on February 4, 1949. While she was still in the hospital Helen cleverly created hand-made birth announcements in a baseball theme, tied together with blue ribbons. They described Johnny and Freddy, as far as what “inning” they were born in (time of day), and their “batting averages” (their weight).

It seems as if it would be a wonderful life for her, and it was; living in the beautiful Northeast countryside, having a loving husband, four bright and beautiful children, and adoring friends. But there was something very, very wrong with Helen Walsh. She couldn't breathe.

John says, “I think at first they thought it was asthma. She was on the original bronchodilators. You know, the little squeeze tube. We thought she had some lung disease, but they couldn't figure out

why at such a young age and with such a healthy background, she'd be a sick as she was. We kids knew Mom was sick, but we had absolutely *no idea* how bad it was.

“She was a very proud woman. She didn't want us to know how badly she felt. Mom would build up the courage to be there for us when we got up for breakfast and get us out the door. We know now, it was after we left for school that the neighbors would come in. They would help out. Mom would rest as much as possible during the day and then make sure she had the energy to greet us and help us with our homework and everything when we came home. Then she'd divide up the chores. We all helped, but it was a while before we knew we *had* to help because she couldn't do it. I mean – helping – it was part of our family culture. It was a tradition we were brought up in – sacrifice and helping others.

“And then Saturdays when we were around, she always had a migraine headache. Freddy and I couldn't figure out why it was that during the week she'd seem functional and on Saturdays she wasn't... And then on Sundays when we went to church, there would be a lot of reasons why she just wasn't able to come with us. And I mean, when we look back at it now, and that – being unable to function as a normal 30... 40-something-year-old mom – that was her day *every* day.”

Fred recalls, “I remember her being skinny, struggling, her nose was running all the time, but she never once complained. Never. Ever. But she was hiding something. She was hiding what she was going through each and every day. I think back now and realize that she never went up the stairs *with* me. She always went ahead or behind, because when she got to the top, she couldn't catch her breath.”

John and Fred were just ten years old when their mother first went on oxygen. Sisters, Susan and Judy were ages 13 and 7. John says, “All I remember about it was that there was this green bottle and that she had to use it to help her breathe. Mom had frequent pneumonias and very difficult breathing on any exertion in the last few years. She had very limited mobility, and there was a point toward the end when she just stayed downstairs.”

In spite of her sickness, Helen continued taking care of her family, using every ounce of energy to raise her kids and be there for whomever needed her. The Walsh kids were busily involved in scouting and school and church activities. John was president of his class and organized his friends in a small business doing odd jobs for neighbors.

John says, “Then Mom went into the hospital for the very last time. We had not internalized it. We just didn't have a clue she was that close. She never let us know just how sick she was. I mean, we knew she couldn't get out of bed, and she had the O2 [oxygen] on. But we never thought she'd *die*.

“Mom was in the hospital. My grandpa – her father – died and we kids went to the funeral. My dad stayed at the hospital with mom. We came home from the funeral, and were walking up to the house, and saw that dad was on the front porch. We saw him – and we knew. *We just knew*. That was the first time I really understood what death was about.”

Helen Chase Walsh died at age 46 as a direct result of complications from emphysema, leaving her husband Jack, daughter Susan, 16, twin boys, Johnny and Freddy, 13, and Judy, 10. She died in 1963, the same year her mysterious killer was identified at a medical research lab in Sweden. It was Alpha-1 Antitrypsin Deficiency.

*For the rest of this story telling of the Walsh family's battle with Alpha-1, the birth of the [Alpha-1 Foundation](#), and other Alpha-1 stories as well as information on Alpha-1 Antitrypsin Deficiency, read **Breathe Better, Live in Wellness: Winning Your Battle Over Shortness of Breath**.*