

A Legacy of Hope Lives On in Cheri Wallace Lindle and Thyca's ATC Listserv

in fond remembrance of Bob Collins - "the father he didn't have to be"

When one is diagnosed with anaplastic thyroid cancer (ATC), what hope is there? All ATC patients die within eight months. That's what all the ATC literature seemed to indicate prior to 1998. In fact, some experts said there had never been a documented case where a patient had survived beyond eight months from initial diagnosis.

Cheri Wallace Lindle desperately hoped the experts were wrong after learning that her stepfather, Bob Collins, was given that same dreadful prognosis on September 29, 1997. While Bob's doctors didn't come right out and say there was no hope, the literature Cheri was directed to on the subject matter made it very clear: having ATC was a certain and quick death sentence.

"We were given a bleak prognosis. We were all in shock and denial. Most of all, I was terrified," says Cheri. And when she wasn't terrified, Cheri was angry...angry that this could happen to this wonderful man whom she fondly referred to as "the family's knight in shining armor."

"Bob entered our lives in 1975 when I was just 15," recalls Cheri. "I was acutely aware of the financial deprivation that my family had experienced before Bob came along. My mom and my little sister, my grandmother and grandfather all lived in a three bedroom trailer. When Bob married my Mom, life changed for all of us," says Cheri. Bob was a man of faith, a church lay leader who was not only generous with his worldly belongings, but more importantly to Cheri, he was generous with his time.

"Bob gave me guidance, discipline and love, and treated me and my sisters as we were his own children. As one country song puts it... "He was the father he didn't have to be," says Cheri. What Bob gave the family and Cheri was an abundance of understanding and hope. "I was looking for a miracle for Bob. I was desperately trying to give back to the person who had given so much to me," recalls Cheri. So, in September 1997, the same night Bob received his prognosis, Cheri began a torrid and relentless search for hope.

Bob and his family's ATC journey had just begun, and while Bob was open-minded and very practical, Cheri grew angrier by the day. Not only was Cheri crushed because Bob had been given a virtual death sentence, but she was disheartened because she had to spend so much time (time the experts said Bob didn't have) searching for the smallest morsel of hope. Cheri soon began re-channeling her anger, spending countless hours each day on the Internet trying to find answers. "I talked with people all over the world: doctors, researchers, cancer treatment centers, and people who had been diagnosed with the same form of thyroid cancer. I read a lot and probably sent out hundreds of emails searching for hope," says Cheri.

In January 1998, in an AOL chat room for Thyroid Cancer, Cheri found two rays of hope, Kathy (from Michigan) and Bruce (from Connecticut), who each had a parent who was diagnosed with ATC, both within four months of Bob's diagnosis. In a recent email to Cheri, Kathy writes: "I will never forget



Cheri Wallace Lindle didn't find



a miracle cure for the ATC that afflicted her stepfather, Bob Collins (left). However, in his journey she found eternal hope which she selflessly shares on Thyca's ATC listserv.

the warm, loving, calming presence you emanated."

Cheri, Kathy and Bruce started to talk regularly and shared the different medical approaches that their parents were experiencing. After two months, they began to find others who were affected by the disease and, soon after, placed everyone's email address in their electronic address book so they could communicate as a group via email. They shared loved ones' treatments, their positive and negative results, and any glimmers of hope. "It was a place to vent, discuss new research findings and provide solace to one another," says Cheri.

The informal list grew to 50 people within a few months and began to attract doctors who were curious as to what the group was finding and what kinds of treatments and results different people were experiencing. In 1999, with the goal of sharing this information with a larger audience, the email group was placed on Yahoogroups. As a result, anyone searching for "anaplastic thyroid cancer" today can find extensive information and support online through the ATC listserv. To sign up, please go to thyca.org/email.htm and select Anaplastic. Today, there are over 100 members of this group and many

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of their ATC journeys are chronicled there for all to see.

Although Cheri did not find a medical miracle for Bob (Bob died in April 1998), she did find hope that she continues to share with ATC patients and their loved ones. "Cheri is amazing," says ThyCa Board Chair Gary Bloom. "Here she is five years after the death of her stepfather, and she's still selflessly providing knowledge, solace and hope to anyone looking for it. Most people who lose a loved one will, understandably, sever their relationships with any reminders of their painful journey," says Bloom. Despite this, Cheri's commitment and resolve have strengthened over time. She honors her stepfather's memory by actively responding to requests from individuals for information and understanding of the disease. and providing hope to others who find themselves in these unfortunate circumstances.

Cheri provides this service for personal reasons, some too deep to articulate and deflects her role as a caregiver, giving much credit to her mother and Bob's parents and sisters. "Emotion sweeps over me every single time because I remember what we went through when we were first learning and there seemed to be so little hope," says Cheri. She painfully and fondly remembers how Bob, when asked if he was afraid of the radiation, told his wife that he thought of it as a John Wayne sharp shooter aimed right at the cancer. She recalls her parents spending long hours together holding hands, taking care of business and sharing long private cries together in their bedroom at night. She remembers how Bob's neck burned so badly from the radiation and yet how he would refuse pain medication and still go to work, doing this up until his last month

of life. She hurts for Bob's mom, who is in her '80s who held her dying son's hand as he slipped away before her eyes on April 9, 1998.

Despite these vivid memories, Cheri's sadness is no match for the empathy, compassion and gratitude she has for people who helped her family through their journey. "I was thankful that others took the time and energy to share with us when we were first learning about Bob's cancer. ThyCa continues to show me enormous amounts of compassion and support, and is filled with individuals who care. They give me the strength to do what others did for me," says Cheri.

All Cheri has to do is remember how desperate she was at the time. "It gives me immediate energy to tell ATC patients and loved ones that 'real' hope is present, which is evidenced through the survivors' stories on our list. I can't wait to tell them of Jan, Clayton and Mary, three ATC patients who each lived years beyond their expected prognosis after their initial diagnosis. "I am eager to share with them the different treatments that have been shared on our list and

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give them names of worthy and successful clinical trials, as well as the names and phone number of those people who have experienced success with them," says Cheri.

Cheri plans to remain active with ThyCa and the ATC listserv as does her mother, Juanita Collins Thorp, and encourages others to offer the hope her stepfather so selflessly shared with her. While Bob was the father he didn't have to be, Cheri was the daughter she didn't have to be, as well as the ATC friend she doesn't have to be.

On behalf of ThyCa, we thank Cheri, Juanita and all the other volunteers who give so selflessly and ensure that Bob's journey and his legacy of hope lives on forever through ThyCa's ATC listserv.

Cheri Wallace Lindle's ATC Words of Wisdom

- 1.** Do not give in to the idea that ATC is a death sentence.
- 2.** Know that there are survivors.
- 3.** Get second opinions.
- 4.** Insist to be seen by doctors immediately. Don't tolerate being put on a waiting list.
- 5.** Go to your appointment with questions in hand and with another person who will be less emotional.
- 6.** Voice and share your fears with your loved ones and with others who have walked in your footsteps.
- 7.** Laugh. It can't hurt.
- 8.** Time is precious; spend it with those you love...doing the things you enjoy.