

Speech given by Mike O'Connell,  
Live Like Andi Foundation Director  
At "Doe Days" Golf Outing  
July 2010

Good evening. Thank you so much for having me here this evening. My name is Mike O'Connell. I am director for the Live Like Andi Foundation. The Live Like Andi Foundation was formed over 3 years ago by my three kids and I to honor my wife, Andrea Whitesell O'Connell – Andi- who died from a rare cancer three summers ago called Adenoid Cystic Carcinoma. Most all of you know what our foundation is about. Some of you have attended our annual Run for a cure that we've held in the spring the past 3 years. But running races or golfing may be high on the list of many for recreation but this....THIS evening...this is pure Andi! ....I know she made time for her spirit to be part of this event today ....and we are so glad to have her with us. This evening is so Andi because it brings together girlfriends, conversation, laughs, hugs, a drink to toast and above all getting dressed up looking your best..... and most of all purses & JEWELRY!

I would like to thank all of you for selecting our Foundation as a beneficiary for your cause. I would like to personally thank all of you that put this event together....especially Kelly Ragatzski.

The foundation is entering it's 4<sup>th</sup> year this fall. In that time the foundation has been a wonderful way to raise money and awareness for ACC and to share with others what a positive life force Andi was to all who knew her.

To date....The Live Like Andi Foundation has raised close to \$250,000. With most funding ACC research directly, we have provided scholarships to more than 12 HS students facing cancer, difficult obstacles to overcome – all with the same attitude as Andi. Our ACC research funding isn't a general donation to a large group that may get lost in administration....this is direct funding for ACC to find its cause, reason for progression and find what will stop progression and eventually cure those afflicted.

ACC is rare. Perhaps only 6,000 people live with ACC today. That is small compared to the 1.4 million living with cancer. But this is more personal to us than being rare. We were all touched by a person who had this disease.....Andi is the reason this cancer is rare to us. Andi is the reason we fight for those....we knew what she went thru and we know she would want us to help others who have it. Today alone, 1,500 people will die

from cancer. 3 of them will die from ACC today. During her battle, Andi was always fighting. Never giving up. She was scared and cried often but never asked “why her”.

ACC by government standards is rare. ACC is too rare to warrant research funding to find a cure. But I have met ACC patients. And let me tell you... the people it afflicts are EVEN more rare. ACC is a relentless disease with a determined course. But the people afflicted by ACC are MORE relentless and determined. The Foundation is a tribute to not just one ACC patient’s life. It is a tribute to all ACC fighters and their family. A tribute to the lives that ALL ACC and other patients stricken with hardships or disabilities endure. A tribute to the spirit and the hope that burns brightly in those afflicted. A tribute to ACC patients like Andi. Andrea Whitesell O’Connell. In the end, ACC may have taken Andi.....but it never took her will to live.

I want to tell you a short story about Andi. It’s a story I witnessed firsthand. It is a story that all ACC patients can tell. A story that one may view as sad...with a sad ending... but it is a story of amazing courage.

As we prepare for her Dr. appointment, it is noticeably quiet. The car ride is quiet. There is no radio or discussion...just the silence of our thoughts. The only communication is an extended hand to hold. A glance that says “I love you”.... no matter what happens. This is a story ALL ACC patients have lived numerous times each year. Andi lived this story over and over many times in her fight. Some patients call it ....”the scan dance”. Doctors call it “routine or periodic screenings”... me?.....I call it “torture”...your life....her life.... held in a scan... an x-ray report. Imagine....if you can enduring such a heavy and emotional life changing experience every 4-5 months of your adult life. How can one live with this hanging over their heads...every day?

We wait.....and wait....and wait.....on these days...the wait seems so long. We are uncomfortable to talk about anything. Any topic seems so distant...so unimportant than what is heavy on our minds and hearts at this moment. We fumble through a discussion anyway...just to help distract us or lesson the pain. As always...a fumbling outside the door is the warning that the doctor is pulling the chart from the bin outside the door. We both anticipate another five minute wait as he reads the radiology report ....yes...for the first time.

The Doctor enters the exam room after what seems like an eternity. The thick, heavy tattered file.... already too full to handle all of the reports, contains yet another....this most important to date.....her life.....her future...her dreams...they’re hanging in that file. The Doctor always remarks “Andi you look so good.” Despite her agony to know her latest fate....her overwhelming temptation to run screaming from the room. Andi ALWAYS smiled. Yes SMILED. To this day it bothers me...but that was Andi. She would then (through the torture) literally carry on a conversation and exchanged

pleasantries...she would comment on "how nice" his stupid tie looked or how his trip to Florida went this year. This to me was precious time wasted...but Andi was always civil and polite. He would always begin an examination of her before telling us the results. A meaningless exercise to her...her eyes darting around the room. Full of pain...holding back tears. Her quick looks to me said..."take me away"..."help". It was always sooo painful for me to watch ...I cowardly looked at the floor waiting for him to finish. Her sweet body exposed to this stranger...covered in scars... from so many major surgeries. They cut her open soo many times it seemed they had no clue what they were doing to her. He listened to her breath. She covered herself as best she could while he listened...her scars....criss-crossing around her torso. What was he hoping to hear this time...her left lung was completely closed off from tumor. The right lung was nearly filled with tumors. At this point we always looked for any remaining dark areas on the x-ray for a spot she could take a breath. He finally pulled the stethoscope from his ears and patting her back or knee to console her. He would say "go ahead and get dressed hon."

Buttoning her shirt and looking nervously around the room.... awaiting the news...she always looked to the ceiling and took a deep breath. Perhaps to gain her composure...perhaps one last prayer to God to make the news good ...just THIS one time. "Please God" I would beg to myself, "...she's been thru so much...she deserves good news this time". The Doctor running his finger across the report like a speed reader as if to scour it for any bit of good news. (pause) The news was not good. Our hearts sunk. " I'm afraid the tumors have spread." "The tumors have grown." "There are new spots". The doctor commenting on their size changes "8mm is now 16mm." andi always looked to me for my engineering brain to show her how big 16mm was with my fingers. As she took in the news..... tears streamed down her face....she bit her lower lip as it started to quiver. The latest experimental drugs she had taken did nothing. She lost her hair (again) suffered vomiting daily, peeled layers of skin from her hands...feet and inside her mouth... "She went through that hell for nothing?" I demanded! With no answer...as always....no idea what to do next...the doctor would close the file placing his hand over it as if to give it...her...her last rites....and ask US....that's right...ask us! "what would you like to do next?" As anyone would expect her to fall apart in tears...Andi wiped away her tears....clenched my hand tightly ...took a deep breath and motioned to me for her binder. Her battle bible....of reports....clinical trials...internet downloads....any piece of hope she could put on paper. As she fumbled thru wiping tears and finding her list of questions she had prepared.....she always avoided the obvious question...we may have never thought and certainly NEVER uttered.....she would finally gain enough composure and ask "well....do you have ANY ideas?.....what can I try next?" The doctor rubbing his head in bewilderment would let out a long sigh...a sigh that said many things..."I give up"... "I have nothing"....."I don't know"....."there's really nothing I'm afraid" He was right....I was afraid. Andi was afraid

too. But she was tough. Not the toughness you see in a football player on the field...tough to make the difficult decision. An inconvenient decision. A hard decision. A decision to try the next drug. Fly off somewhere in the country to find it. And... relentless and determined - resigned to try the next drug, the newest inhibitor or chemo. What I witnessed was pure courage. What I witnessed was an amazing toughness...Filled with her hope...I promised her I would fix her. This was a promise I was unable to fulfill to Andi. But knowing Andi, it's a promise we can make to the ACC patients who live this story over and over in their lives.

This may seem like a sad ending to a sad story. But here is where we can be part of the promise....The promise to give these ACC fighters the hope and spirit that Andi had. We can rewrite the ending of this story for all of those fighting ACC today.

The Live Like Andi Foundation (through contributions from great events such as this) is proud to be funding the 1<sup>st</sup> EVER Phase 2 Clinical trial for a treatment specifically for ACC patients. Hope for those with ACC who may face the same decisions and fear that Andi faced. The clinical trial was just approved and will be conducted by the Karmanos Cancer Institute here in Detroit. Beginning in September, 15 ACC patients will begin treatment for their ACC.

If each of us could have ...just a bit of the spirit, the happiness and the pure joy that Andi had just to be ALIVE...what a wonderful world it would be. Take that little bit of joy home today if you get anything out of this event.....

As we are 3 years this Saturday from saying our goodbyes to Andi. I still have so many more questions and fewer answers. But today I have something....Something that I did not have before. Today I have something Andi had every day she fought ACC. I have perspective. Andi lived everyday of her life as if it could have been her last. She lived like this and kept this to herself so as not to worry others. But the perspective she had living with cancer showed her how precious life is. She hugged everyone she met with a special love, she smiled more often than anyone I knew. She was truly happy..... to just be alive. Carry that with you today....that "perspective" .....Andi's perspective. Give your spouse or kids a special hug everyday (like Andi). Say "I love you often" Like Andi. Smile when there may be no reason to smile (like Andi) be courageous and never give up (like Andi). Live like Andi everyday of your life.

*Thank you all for your continued support and especially .....Thank you Andi!*

God Bless you  
[www.livelikeyandi.org](http://www.livelikeyandi.org)