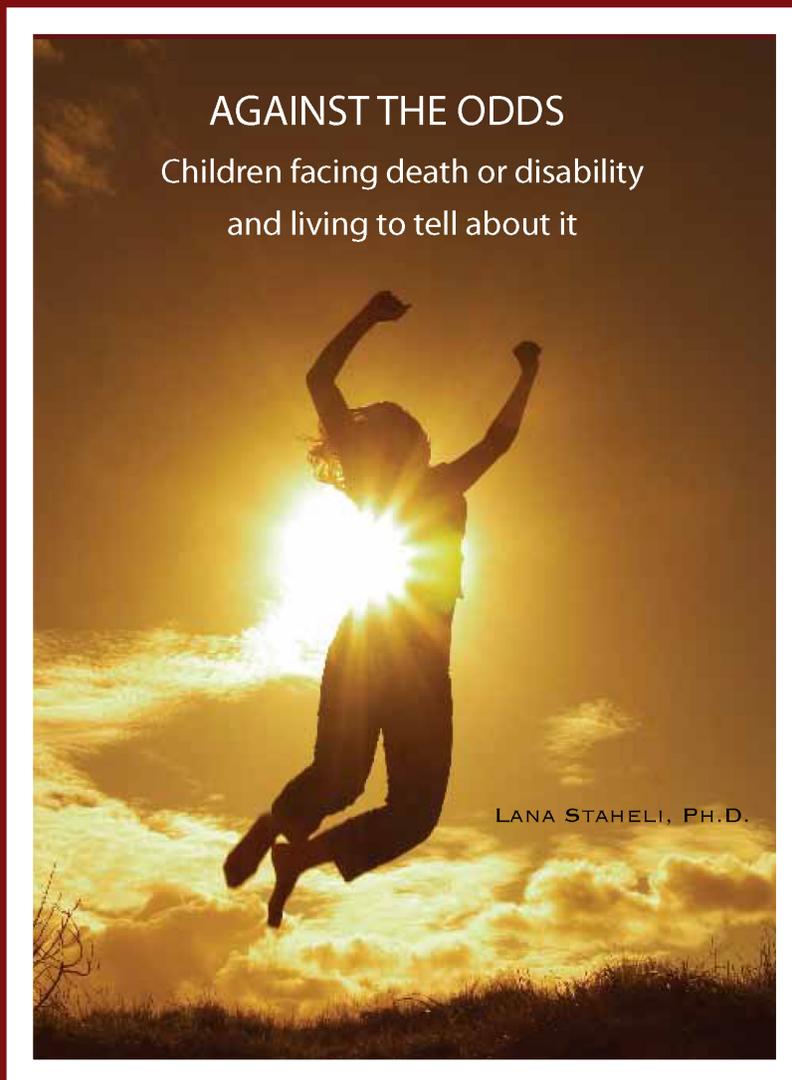


Against The Odds: Children Facing Death Or Disability & Living To Tell About It



Lana Staheli



Global HELP

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TP DEBBIE.

THE TIDE RECEDES, BUT LEAVES BEHIND BRIGHT SEASHELLS IN THE SAND.
THE SUN GOES DOWN, BUT GENTLE WARMTH STILL LINGERS IN THE LAND.
THE MUSIC STOPS, AND YET IT ECHOES ON IN SWEET REFRAINS... FOR EVERY
JOY THAT PASSES, SOMETHING BEAUTIFUL REMAINS.

– UNKNOWN



STORIES OF BOUNCE
EACH STORY IS A GIFT

Against the Odds, facing death or disability and living to tell about it, is a collection of stories by people who faced death or disability during childhood and survived. They did more than survive, they thrived. These are people who transformed themselves through their struggles. We call this transformation, BOUNCE. People who BOUNCE use their energy and abilities to completely change themselves, for the better. They look ahead, not back. At times when others might give up, become locked in their past, or become bound by fear, they don't get better, they soar beyond better, way beyond.

Those who BOUNCE create futures that are not variations of their past. Our BOUNCE storytellers rise above and far beyond where they had been before. They channel their energy in entirely new directions. It is our hope that these stories will offer you the perspective of others who struggled with medical problems all during childhood. Most of our contributors are now adults who share their wisdom, as well as humor.

These stories offer more than inspiration and entertainment, they offer healing wisdom. Recent scientific research has shown that chocolate, laughter, beauty and pleasing aromas, significantly aid healing. MRI's (magnetic resonance imaging) show that the brain signals the body to produce and release natural healing hormones called endorphins. On the other hand, fear and anger triggers the brain to send steroids. Steroids cause diseases like arthritis, high blood pressure, even cancer.

The triggers for the release of endorphins comes through the senses. Taste from foods like chocolate and spicy sauces, smells of perfume or fresh bread, sight of a loved one or a pleasing picture, or sounds like a lullaby or a water fall, all call for the release of endorphins.

By far, the best trigger for the release of endorphins comes from person to person contact. A gentle touch, a friendly smile, or a compliment, all signal the brain to order the release of nature's healing potion. Best of all, laughter floods the entire brain with endorphins and we feel great! When we laugh together, especially a full-blown, raucous kind of laugh, those that you can't stop chuckling afterwards, are the very best.

We have put together these stories in a way that will stimulate the release of endorphins for you. We have stories with important messages, stories with humor or incredible courage. We have pictures to add to your understanding and other images simply to give your eyes and brain a little joy. Some images are from the author, others are stock images.

LET YOURSELF BE ENTERTAINED AND INSPIRED. LET YOURSELF BE TRANSFORMED.

LET YOURSELF BOUNCE.

Sincerely,
LANA
Lana Staheli, Ph.D.



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RAINIER
FOUNDATION

Elizabeth's Story

Asthma and Allergies

ELIZABETH IS ACTIVE AS A PHILANTHROPIST AT CHILDREN'S HOSPITAL AND REGIONAL MEDICAL CENTER IN SEATTLE. SHE IS CREATING A RESEARCH PROGRAM FOR THE STUDY OF ASTHMA AND ALLERGIES IN CHILDREN. SHE'S A MEMBER OF CHILDREN'S CIRCLE OF CARE AND A CONTRIBUTOR TO THE STAHELI CHAIR FOR RESEARCH AND EDUCATION IN PEDIATRIC ORTHOPEDICS AND THE BOUNCE PROGRAM.





Childhood home and family



Asthma is chronic disorder characterized by shortness of breath, wheezing, coughing and tightness of the chest.

Anaphylactic Shock is a serious and rapid allergic reaction, often fatal for children in the 1930's.



Eczema is painful. The rash of eczema is itchy, red and symmetrical across the body. It may become dry, scaly and cracked, oozing yellowish fluid and forming crusts.



The rash may develop anywhere on the body but in younger children the face, cheeks, scalp, forearms and front of legs are most commonly affected. In older children, the rash is usually more localized to flexures (the inside surfaces where joints bend the skin, especially at the wrists, elbows, knees and ankles).

As I was growing up, I rarely felt that I was different than anyone else, but in actuality my upbringing was quite different because of health issues. I was born in January of 1933 and I have a sister four years older. We lived comfortably north of Seattle, and our family was very close, including grandparents, aunts, uncles and cousins.

When I was a few months old, my mother added egg to my bottle formula, as this was done in those days for extra nutrition. I immediately had an allergic reaction, and to this day, nuts and eggs cause me to have an anaphylactic response.

As time went on, I developed eczema and asthma, the later being triggered by childhood colds. Consequently my education was interrupted for long periods of time each year, and I was withheld entirely from attending the fifth grade. It was not until the middle of the eighth grade that my doctor felt I could handle the exposure to classroom colds. During those years, I was tutored when I was not in the oxygen tent or recuperating, so my education consisted of the basic three Rs, at best. At the same time my eczema was at its worst, so my beloved piano lessons were hit and miss.

Wheezing and struggling to breathe was exhausting, monotonous and boring, but I never was concerned that anything might happen to me. I just accepted this malady and knew I would some day get better.

I dearly missed associating with my school friends and playing the usual neighborhood games of hide and seek, bike riding, etc. Going to summer camp and overnights at friends were out of the question because of my food allergies and a chance of a sudden spell of asthma. Even though I could not participate in these normal activities, I still never thought of myself as being different. I credit my parents for this feeling. It never occurred to me that my friends might think of me as being sick.

These years were very difficult for my sister as her activities were curtailed since many family activities were designed around me. I never remembered hearing a complaint from her even when the family took me to an allergy specialist in Philadelphia. This month-long trip in 1943 took her out of school during her freshman year of high school. To this day, I credit the strong family love and respect for one another for a part of my healing.

There was particularly one time, I later realized, that my parents thought they might lose me, but this was never discussed. It was my mother who was always there to give me that shot of adrenalin when needed. This time my father gave me the shot and sat by my side holding my hand.

Since I spent many weeks and months at home, I learned to enjoy the many crafts and quiet activities that my parents made available to me. Consequently, to this day, I am just as content pursuing my own interests as functioning in a group. During my years at home between these bouts of asthma and eczema, I lead as normal a life as possible. Because of my reclusive lifestyle, it became harder and harder for me to step into the main stream with my peers. When possible, my Mother would arrange for me to attend an art class or event at school, and it took extra courage to suddenly present myself, especially in middle school. I remember with pleasure the little moments, when the curtain around the oxygen tent would be moved aside and that meant I didn't need as much oxygen and I was getting better.

I still cherish and enjoy simple pleasures, as I take time to notice the beauty of the garden, the ever-changing lake, and the morning sunrises.

I never wanted to be different than others or stand out. Obviously, I was very naive. I learned to not let a disability consume or control my life any more than necessary and to develop interests outside.

Looking back over my illness, I feel I learned that the mind can play a very major role in the healing process. The nurturing and love given by family and friends and a very capable and caring physician had a very positive role. All of this taught me about building and strengthening of my ability to face new and monumental problems, and to always be thankful for the present as my situation was not unique from many others.

These lessons paved the way for me to cope and work through different kinds of challenges I had to face in later years. I feel it gave me an inner strength to deal with situations out of my control, but this was also obtained through the help of others. Childhood illness left me socially and emotionally innocent and trusting.

During an asthma attack at college, I called my mother to take me home. While I was waiting, the house mother, a Christian Scientist, spoke with me in a comforting voice about the beauty of the trees that time of year, and as we talked my wheezing stopped. By the time my mother arrived the attack was over. That lesson has helped me many times. When I have had an allergic reaction and needed to get to the hospital immediately, I say to myself, "Don't worry, we will get there in time. Don't worry".

This may be why to this day, I do not have fear when I am being rushed to the emergency room when a piece of nut accidentally falls into my food. I do not let my food limitations interfere with my social activities, as a missed meal is never a problem.



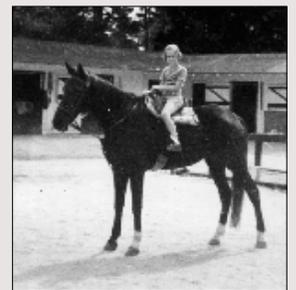
Oxygen tents were used to make the oxygen level higher than the normal air, making it easier for me to breathe without coughing. Mine was made of dark green plastic.



In the 1940's kids sometimes used inhalers, but I didn't.



I had a happy childhood and I did the same activities as other kids. I rode my bike, went horseback riding, played at the beach and swam. My sister and I each had cocker spaniels.



My oxygen tent was replaced by normal bedroom dolls and bears, and then by more grown-up things.



My college years were difficult as my social skills were very elementary compared to my sorority house peers. The same held true for my education, as at this point I had only been out in the real world and attending school regularly for four and a half years. I felt very inadequate in the area of literature and writing, so I struggled through many courses. The entrance requirements at the University of Washington were not as demanding in my day as they are now. Through the years I was taught to stick with whatever you were doing, so this perseverance made up for some of my lack of early education.

After completing four years of college (I did not graduate), I was swept off my feet by a charming young man, and we were married less than a year after meeting each other. Twice when we were dating, I considered calling off the wedding, each time he had become angry, too angry for the incident, but I was not worldly enough to recognize these quirks as real trouble ahead. I thought of telling my mother about my concern but when she asked me if everything was OK I quietly said, "Yes" and she did not question my hesitation. So, we went ahead with the wedding. When we returned from our honeymoon my mother had destroyed all my photo albums that contained any pictures of me with past boyfriends. All of my pictures from high school and college days were gone. My new life was with my husband.

I never heard my mother criticize or seriously question my father. I thought they had a good marriage and I would emulate them.

A bad temper and a controlling personality did not foster good parenting and a strong marriage. My illness plagued childhood and the way I was raised taught me to accept, not fight, his actions. Most of the time, acceptance is a gift I am glad to possess, but at the time I married a little more questioning and discussion would have been a good idea. I didn't know how to talk about problems or concerns or who to talk to.

Our life together evolved into what I thought it should be. He worked at the bank, we had two children and a nice home, and under my father's encouragement he was promoted rapidly. I never challenged anything my husband did or said, as my upbringing taught me it was not appropriate to argue.

I was aware that my husband had some disagreeable relationships including my sister, her husband, and our cousins. I, of course, sided with my husband without question and my sister and I had limited contact for many years, except when we were helping our parents during their years of illness.

In all, I felt I had a very wonderful life at last. I was able to manage my allergies and asthma (thanks to new medicines.) My job was to raise our two children and become involved in community activities. I loved caring for our children and being part of the community. I was a hostess for friends and business associates. I had grown up with the sense of civic and community interest and responsibility. My parents instilled their values in philanthropy and community service by example.

My mother cut patterns from 5 layers of fabric to be sewn for clothing for refugees during and after World War II. We put together boxes for service people. I supported the Children's Foundation at Everett General Hospital volunteering and fund raising. I enjoyed my children and their friends and my husband and his colleagues.

I played tennis and golf, as well as bridge, with friends. I was active in several charities especially those that cared for children. The middle years of our marriage were good. Our children were doing well in high school and beginning college. Our life was normal and routine. We had good times traveling together and with friends, but increasingly he fell apart, if everything didn't go his way.

As time went on, my marriage was becoming more difficult, looking back, the change was gradual. I would have never accepted some of my husband's behavior if it had started earlier in our marriage. Over the years, his comments became dismissive, critical and ill mannered. Some of these characteristics I attributed to his childhood background, and others simply became normal in my mind.

My husband had always been very controlling and he became more angry and abusive as the years went on. He controlled all of the money, even the money I inherited from my parents. I had bounced from my childhood illness, but I felt myself sinking under the pressure of his unpredictable attacks as they became more hostile and more physical. Other than our children, my family did not know about the abuse—pride and brain washing kept me silent. I did not know who to talk to about these increasing problems. I felt ashamed, embarrassed and alone.



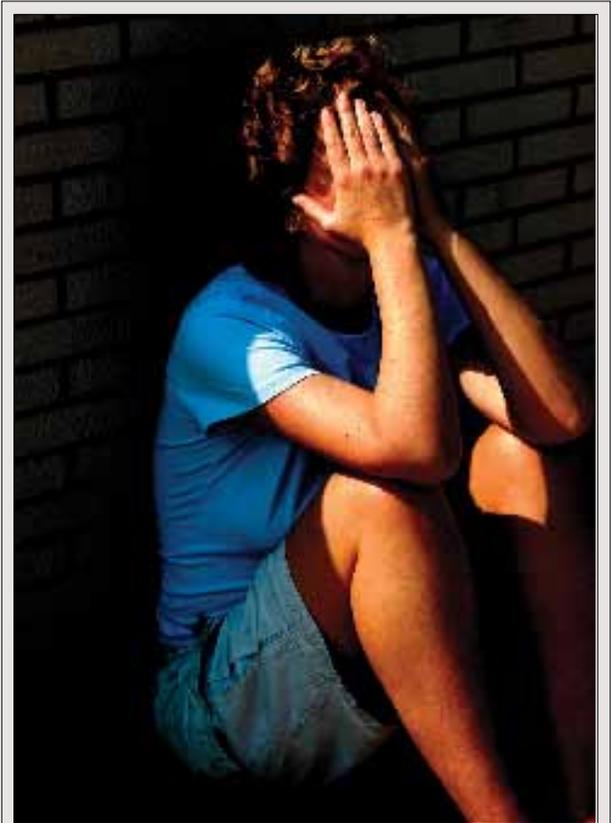
I felt alone and ashamed, his insults and hostility made me feel worthless and stupid. But, I remembered my favorite tutor telling me, "It is always darkest before dawn".



Like the constant dripping of water, I got used to the continuous criticism and humiliation, but the beatings I could not pretend were my fault.



A few years before when I went to sign in at a board meeting and was told I had no stock. I began to ask questions about my money.



I remember as if it was yesterday, walking down the cobble streets of Lisbon, he was rude and cruel as usual, put my hands to my face and sobbed.

Since I had married right out of college and had always been under the care of my parents or influence of my husband. I started thinking about divorce in 1985 after a “small” beating. I went to an attorney, friend of the family, who advised me to get counseling and to try harder to make my marriage work. Staying with him another eight years cost me more than time, as it also cost me my hearing. The repeated shaking and slapping permanently damaged my ear drum.

It had to be done. I had to get a divorce. It was the only right answer, but I hesitated, again. Time passed and our relationship was usually “not too bad”. The turning point was on a Mediterranean cruise with friends.

Arriving at the airport I was thinking maybe I could excuse myself but I boarded the plane with bruised hands and arms, and a very sore hip from where he had kicked me while I lie on the floor covering my head and ears .

One beautiful night on the ship, I stood at the rail as we’re leaving port. I questioned again whether I should leave, this time I decided I had to leave. We rented a car in Portugal and I was to navigate as he drove, when he thought I directed him the wrong way he screamed at me and refused to stop for lunch or sights of interest. I had gotten extra cash on the ship and packed a sweater and slacks in a small tote, as I thought I might have to escape one of his outbursts of temper.

I was further convinced I must take the big step upon returning home and strike out on my own for the first time ever.

I mustered up my courage. I talked with both my adult children. With the blessing of my children, my sister and cousins, I left. I knew I had to stay on course this time. It was always seductive to think things might get better, but I knew from years of experience that we always went back to the same pattern of seemingly normal behavior until the next explosion and all physical and emotional abuse would begin again. I had to forge ahead, and look to the future and end the marriage. I have always lived by a quote from one of my childhood tutors, “It is always darkest before the dawn.” These were truly dark times.

My early experiences of being in and out of school and having to adjust in a world that I could not control because of my health limitations, gave me the courage to step out on my own. I didn’t know what to expect or what I could or could not do, but I knew I had to leave, no matter what others thought.

I tried to talk to him at our cottage with our kids present, but he became angry again. I went home but he followed me. I heard the creak of his footsteps on stairs and ran out of the house and hid at the home of a friend.

Bit by bit, I made my way. I no longer accepted everything people tell me, now I insist on understanding. I have gained confidence and freedom, but it also hurts me deeply to know I have been betrayed by people I loved and trusted.

I learned from my childhood struggles to get professional help. I set up a support team, of my choosing, to advise and guide me through this quagmire and set the scene for this wonderful stage of life. I choose people who I respect and who respect me. My freedom also brought some surprises.

I was overwhelmed by the love of old friends who stepped forward in support of my decision, many telling terrible stories of their dealings with my husband. I was shocked and embarrassed, but with guidance, love and forgiveness of my sister and friends, I found new strength and abilities I never knew I possessed. I bounced, again.

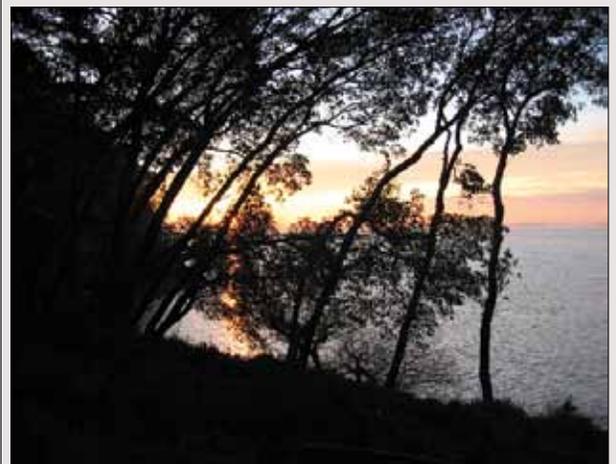
I began making my own way in the world and enjoying a renewed circle of friends. I also became aware of other relationships in my life that I now realized were not normal. It was the first time I felt I could be candid about problems and concerns, and talk to other people about them.

Teaching and nurturing two of my granddaughters is a wonderful part of my life. I found a college for one of them and helped them sort out complicated emotions about their parents and grandfather. I have been able to be an advocate for them and they have given me the opportunity to guide them. We appreciate and respect each other, the way I now know families should.

To this day, I am as grateful for the world about me, as I was during my childhood days, especially those days when I was not wheezing and scratching. Unknowingly, these days uniquely prepared me for a bumpy future and allowed me to blossom beyond my imagination.

Whenever a project seemed so large that I did not know where to begin, I would tell myself to start nibbling. This holds true whether weeding a garden or chasing down lost figures in a ledger. My father used to tell me not to beat a dead horse, as I would keep trying to get something to work when it was definitely beyond repair. Knowing when to quit is important. Quit what doesn't work, and keep going, leave the past behind.

My advise to you, *“Use your experiences throughout the years to savor every day of your life, even though it may not have taken you down the path of your dreams. There are so many hidden pleasures in the world, ranging from observing the first spring blossom to small successes of others. Find joy and bounce: go beyond your limitations—far beyond”* — Elizabeth



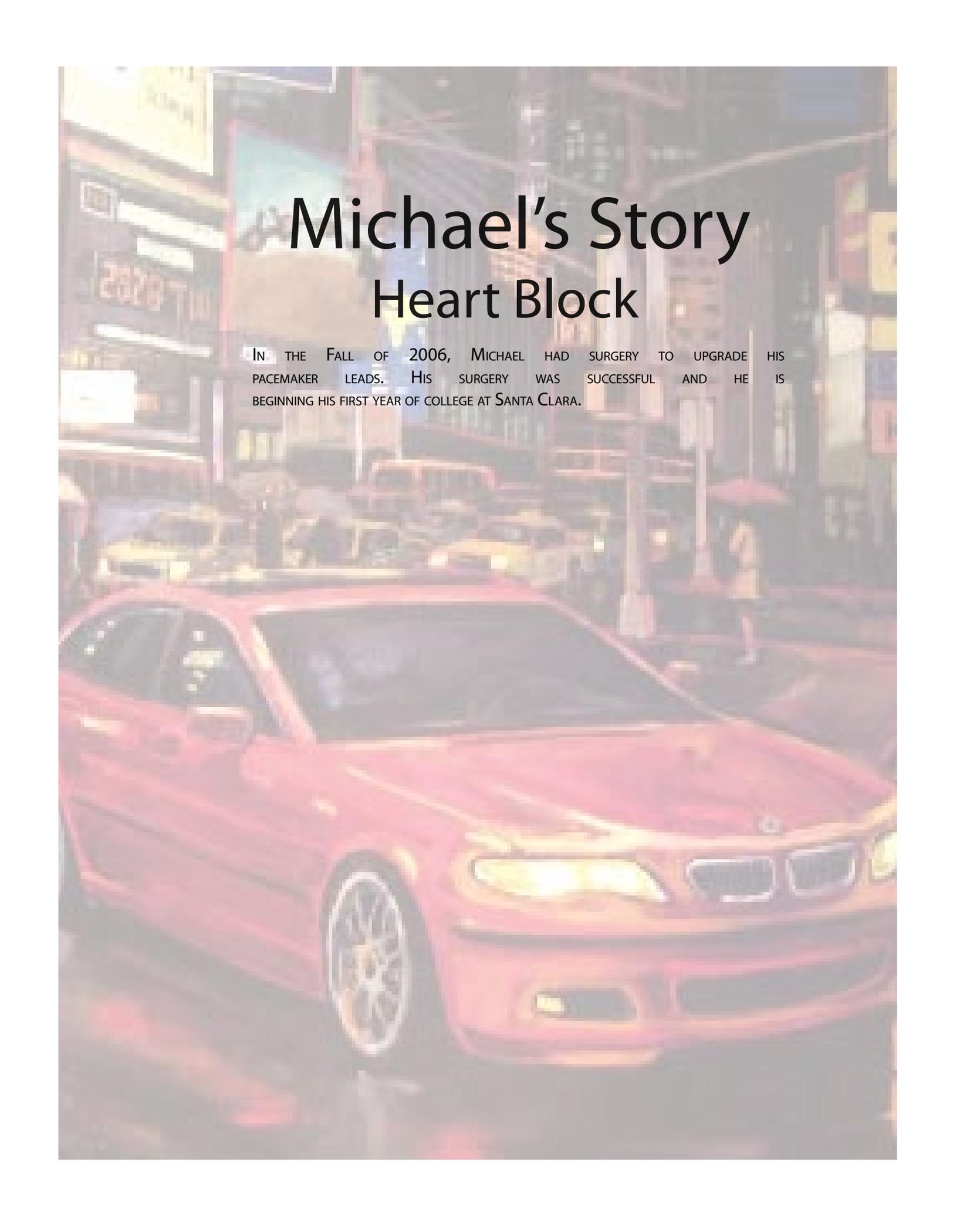
Love life even when it is not what you hoped for.



Deep breathing helps to relax and calm emotions. It provides more oxygen to your body. Follow these simple techniques. Begin by breathing normally, but pay attention to each breath. Then begin to breathe more deeply – inhaling and exhaling longer. With deep breathing, you breathe from your diaphragm, from your gut. Breathe deeply and slowly, focusing all of your attention on each breath. Don't rush. Imagine the tension draining from your body and mind as you exhale.



Take time to enjoy the beauty of everyday.

A blurred night city street scene with a red car in the foreground. The background shows city lights, buildings, and a person with an umbrella. The text is overlaid on the upper half of the image.

Michael's Story

Heart Block

IN THE FALL OF 2006, MICHAEL HAD SURGERY TO UPGRADE HIS PACEMAKER LEADS. HIS SURGERY WAS SUCCESSFUL AND HE IS BEGINNING HIS FIRST YEAR OF COLLEGE AT SANTA CLARA.



Dr. Frank Cecchin. Cardiologist - Boston Children's Hospital



Age 4 - This was when my pacemaker was placed adjacent to my belly button prior to being moved up towards my shoulder

Better Than Before

Everyday, I walk through life looking towards the future but living in the now. I know what my goals and dreams are but I live for the now. I live for each and everyday because I know what it is like to be faced with death and the alternative is just so much greater. I have had to “bounce back” from many painful and rough experiences, but after they are all said and done, I feel like I come out of them a better person. There are three very specific difficulties that stand out to me the most and leave a resonating effect in my personality and my understanding of people and the world. The idea of “bouncing back” is easiest to look at with a metaphor. When a goalie for a soccer team lets a ball go through his legs and score, he comes back into the game with more drive and more motivation than before. The goalie’s realization that the show must go on instills an extra drive and motivation. The battle is no longer over the last ball that he let go, but the way he deals with this loss and how he comes back into the game giving more of an effort. That is the “bounce” method and it illustrates the reality that the game is still on. This definition of bounce is looked at by basically overcoming the downfall, and learning from it to become higher than before. And bouncing is simply golden.

Heart Problem

Before I was born, the doctors knew I would have heart problems. A congenital heart block alerted them to this ailment. This heart block left me needing a pacemaker at approximately the age of 3 months. It was a very large pacemaker of the late 1980’s, placed two inches above my belly button and left of it about four. These numbers are my assumptions about it now but the pacemaker was much larger inside my stomach 17 years ago than it would be now obviously. I say “would be” because since then, I have had two new ones. The first was smaller and inserted above my upper pectoral muscle on my left side, basically at the point in which one can almost feel inside the shoulder socket. This was followed by a physical problem of my heart muscle more specifically, a hole in my heart. Another surgery took place that left me with a nasty, six inch scar coming directly down my chest. This hole was followed by a virus in my heart causing it to enlarge. I was hospitalized for nearly a month and received a new pacemaker in the meantime. The only exterior, physical extremity to my surgeries was my scars, which leads me to them.

For years I have battled with my scars being unsure about who would judge them and in what way they would perceive them. I have realized that all the while they were being judged mostly by me. Honestly, not that many people have asked me about them to my recollection.

Maybe I do not have an honest count because when someone would ask me, the question and answer process always seemed much more painless than I had been prepared for. Maybe people find themselves in an awkward position asking an in-depth question about a physical attribute that they do not share. Many people offer a suggestion of looking at my scars as battle wounds. I can never find it in myself to look at them that way, but I do look at them like this. They are part of you and as different as they are, their permanence only strengthens that individuality. This doesn't mean I'm proud of them, but I have come to the point in my life where hiding is the worst thing I can do.

Parents Divorce

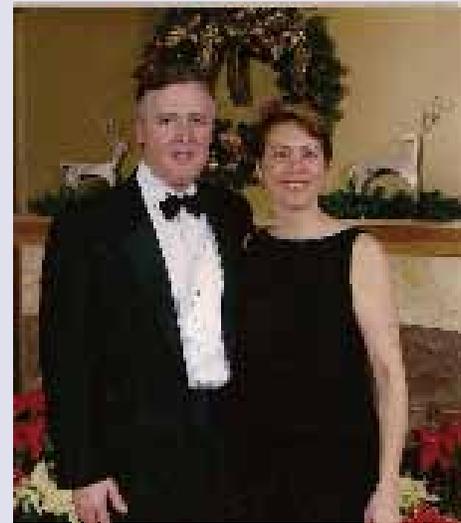
For 27 years, my parents have built and flourished and survived in their relationship. I was 16 and down in Arizona when I noticed the problems first occur. This was the first time they actually hid their arguments from me. Communication wise, my family is very sound and open, but it alarmed me when they felt they had to conceal something and hide it. They had always talked about divorce and even called it the "d-word." But it was so real now and following the trip to Arizona, they separated. It was tough and my bounce came at the point in which I told myself, "I am almost an adult of my own and while only part of my life is in my hands officially, I can act like I have it completely tight. Tight as a football in a running back's grip." I focused on my life and as I look back, it was almost a little greedy, but, so is divorce so I felt no remorse, and I now understand what it takes to make a relationship work.

Friend's Suicide

In my life, I have only had 3 pets that I can remember. My dog, Tiger is still alive today, and a cat named Ellie died at about age 13. My rabbit named Cuddles died around age 11. As it could be said, by the end of 2004 I had never experienced death because at that time I still had all my living relatives. The end of 2004 struck the middle of my Junior year of high school. On March 3rd of 2005, I drove to the aid of a buddy who called and requested help, for his car had broken down. I drove up to his car and saw probably the biggest shock of my life. This shock was brought forth by a scene that only warriors see on a battlefield. My friend had shot himself. Not just a friend but a best friend. A guy that I see everyday. A guy that I hangout with and laugh with. Him and my two other best friends were inseparable. We were always together, living life, and it was at that point that we all felt like we had been shot too.



Current Pacemaker by Medtronic as of September, 1997
- Dual Lead



24th anniversary - 2 years prior to word of the divorce. Final after 27 years of marriage



Jason Allen Levy
(1986-2005) at age 18

"For myself I am an optimist - it does not seem to be much use being anything else." - Sir Winston Churchill (1874-1965)



"The pacemaker patients were likely to be as fearful of social rejection as of potential pacemaker failure. All three groups identified potential negative peer reactions toward an individual with a pacemaker."

Psychosocial responses of children to cardiac pacemakers.

Alpern D, Uzark K, Dick M 2nd.

Division of Pediatric Cardiology, C. S. Mott Children's Hospital, Ann Arbor, MI 48109-0204.

AV block

"Patients with significant AV block often have diminished cardiac output due to significant bradycardia and no AV synchrony. These patients may receive a VVI or DDD pacemaker. The VVI pacer requires that only one pacing lead be implanted and this system functions as a ventricular equivalent to the AAI system described above. Although VVI pacing provides adequate ventricular rates, there is no AV synchrony or benefit from the atrial kick. DDD or "dual-chamber" pacing is an excellent option for patients with AV block, but requires pacing leads to be implanted in both atrium and ventricle."

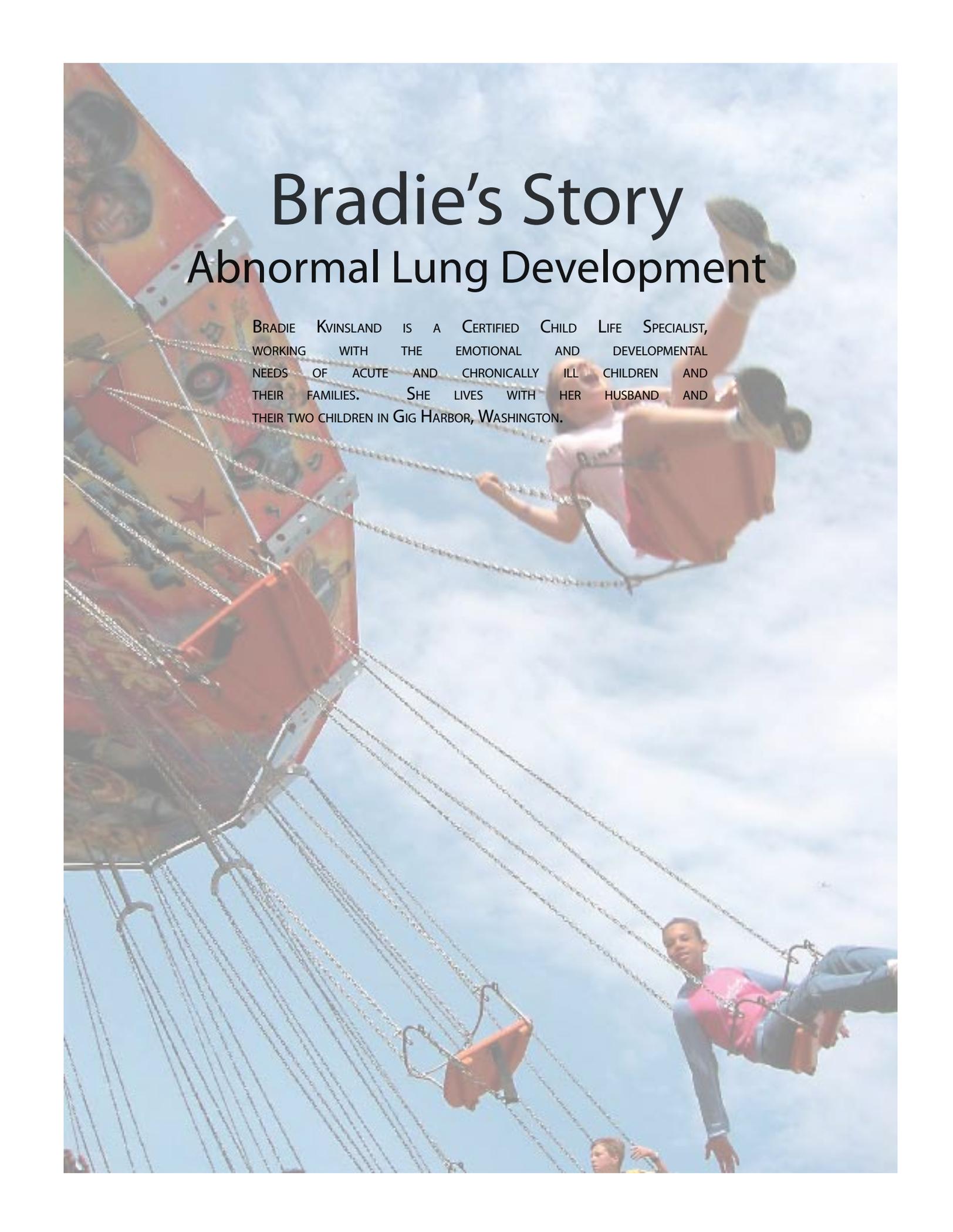
CHRISTOPHER L. JOHNSRUDE, MD

I had never experience death before. I was a virgin to this kind of pain. Grieving was new to me as was the realization of the permanence of death. The times ahead were rough and only continued to falter as the loss grew more tremendous but the strength that I endured through all the tribulation gave me power to see the sentiment and idea that life goes on. I was able to put mind over heart and continue on with the necessity's and goings' on in life that don't stop no matter how harsh the circumstances. The realization of reality kept me going.

Bouncing

I fully attribute the ability to cope with and bounce back from these problematic times to the childhood independence I seek and have received for most of my life. I was an only child so I constantly relied on myself and only myself to circumvent and rationalize feelings. However, some only children are essentially "babied" by their parents and I attribute my mental processing to that fact that I wasn't. Despite my heart problems, I was allowed to live a normal life or as close to it as possible and through this, I experienced traumas and learned reality. No pain was ever shielded from my eyes. I constantly see over-manicured teens that have been blinded, that are just now realizing life and are falling into holes. They have never been faced with reality as a child and have missed out on some of the most important lessons. The lessons of emotional intelligence and mental maturity that prepare one's self for an imperfect future.

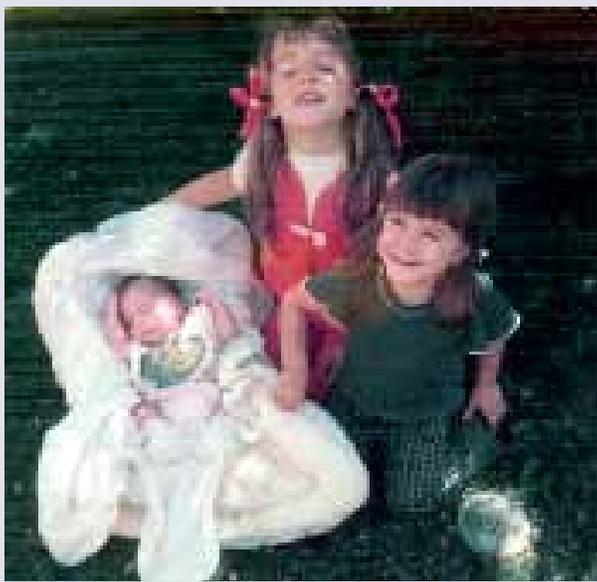
Life often comes in shocks. Things will jump out and leave you in a world of hurt. Unfortunately, that is the way it is and if you understand this and are able to learn from the problems, you can excel forward just like the goalie until you are better than before, living everyday with a stronger mind and heart. The fine line between progressing and flourishing is defined by bouncing.

A photograph of a Ferris wheel with children in colorful seats against a blue sky. The Ferris wheel is on the left side of the image, and several seats are visible, each with a child. The sky is a clear, bright blue. The text is overlaid on the image.

Bradie's Story

Abnormal Lung Development

BRADIE KVINSLAND IS A CERTIFIED CHILD LIFE SPECIALIST, WORKING WITH THE EMOTIONAL AND DEVELOPMENTAL NEEDS OF ACUTE AND CHRONICALLY ILL CHILDREN AND THEIR FAMILIES. SHE LIVES WITH HER HUSBAND AND THEIR TWO CHILDREN IN GIG HARBOR, WASHINGTON.



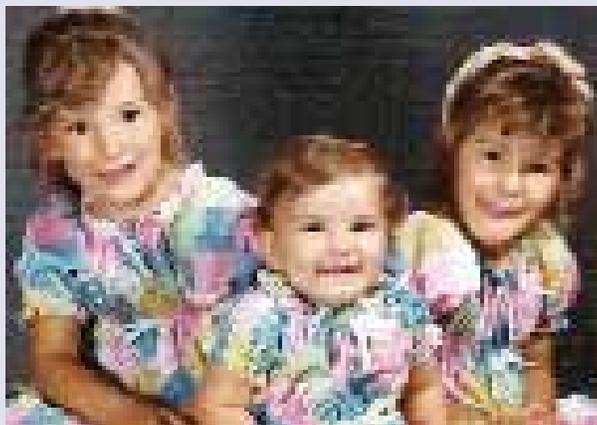
Bradie and Sisters. Bradie is 10 days old (July 26th, 1975)



Bradie, 3 months old. (Oct. 1975) Just before surgery. No record of photos during hospitalizations



Bradie, age 1 (July 1976)



Bradie and sisters. Bradie, age 1 (1976)

My story, even at the age of 30 is told through my father's eyes. I have little to no recollection of the fragile years following my birth. Upon my request, like so many times before, I ask my father to sit down and give me the accounts of my birth and early childhood. A childhood that I do not identify; that at times I have to remind myself 'this is me we are talking about'.

As my father begins to recount the beginning of my life I find myself being drawn into his words as if I have picked up the perfect book and simply can not put it down. Feeling as if, I am being told about a stranger whom I am drawn to learn more about. Each time, wondering if I will make the true connection that it is my life we are talking about.

With sincere concern in his voice and emotional memories of fear and concern (only a parent feels for a child) an account of my illness begins. My father's account of my illness through self interpretation goes as follows: Born on July 16, 1975 to Buford and Barbara Beasley. I was the third and last of three daughters. Both of my sisters, were born healthy and at the time, developmentally on target. My father recalls my mother coming out of the delivery room before me. Instantly, he knew something was wrong. With both my sister's births he always saw the baby first. My mother told him, "It's a girl and there is something wrong with her lungs". This was a shock considering the pregnancy was normal, my mother carried me to term and I appeared to look like a healthy newborn. According to my father my mother was more frightened than he had ever seen her.

The delivering doctor describes the lung tones coming from his stethoscope as hearing "grease in a frying pan". Right from the start doctors were literally scratching their heads trying to figure out what was wrong with me. Being born in a small Wyoming town, the facility was unable to care for my needs. Not long after my birth I was sent to Billings, Montana where a work-up began. The immediate evaluation revealed that I was in respiratory distress and had a markedly abnormal chest x-ray. The doctors in Montana felt overwhelmed and gravely concerned for my life. It was decided that the best care for me would be at the University Of Colorado Medical Center. A sense of urgency was mounting to diagnose my condition and try to save my life. I was immediately airlifted to Colorado Medical Center where Dr. Cotton was to take over my care in the Pediatric Pulmonary department.

Arriving in Colorado the doctors were prepared to see an underweight, gangly infant. My physical state was just not what they expected. I was a healthy weight and thriving.

I was admitted to Denver Children’s Hospital and in the fall of 1975, just a few months after my birth, following an extensive work-up including pulmonary arteriogram, bronchoscopy, and much more, it was decided that it would be best to remove the lower lobe of my left lung. Under general anesthesia the doctors began to unfold and deepen the mystery. I have been told that the doctors working on me that day had never seen anything like my condition. The surgery revealed areas of moderate emphysema, areas of atelectasis, some interstitial pneumonitis and most unusual band of fibrosis and bands of smooth muscle in the extreme periphery of my lung which was the site of the biopsy, and finally scattered small islands of cartilage in the same area. The final pathological diagnosis was hamartomatous malformation of the lung. The doctors did not remove the lower lobe of my left lung that day. Instead, they took a biopsy and closed me back up. They could not then and still have not given a true diagnosis to the condition I live with. I have been told that at the time of my birth I was said to be one of five ever reported to have a similar condition. They simply gave my parents descriptions and labels for the disease. The two most commonly used labels referring to my condition were, ‘she suffers from chronic pulmonary disease’ or ‘Bradie has a congenital birth defect’.

After an extensive stay in the hospital my parents were exhausted. They had two other small children hundreds of miles away in Wyoming, my father was losing income being away from work and they were living with the fear that their child was going to die any day. My father recalls on one occasion when they were drawing my blood gas (which was done multiple times a day) the nurse was squeezing so hard on my finger that “the meat was coming out”. The build-up of stress and concern EXPLODED and my father could not take any more! He recalls demanding that she leave and never return to care for his child again. He was tired of people poking and prodding. He was empowered to protect me.

The final conference before leaving the hospital was one that hit my parents the hardest. “Mr. and Mrs. Beasley, take your daughter home, she will not likely live to see her first birthday”. They were told that I would likely die from a lung infection. My father describes my mother’s response as direct and confident, “what do I need to do to keep her alive”? She was unwilling to accept that I could possibly die. She had hope and determination to fight the disease. My parents were taught therapies to vigorously pound on my back 2-3 times a day. They were instructed that I was at higher risk for recurrent infections and in the event of a fever or cough seek immediate medical attention. With that, they had nothing further to offer and my parents left the hospital scared to care for me on their own.



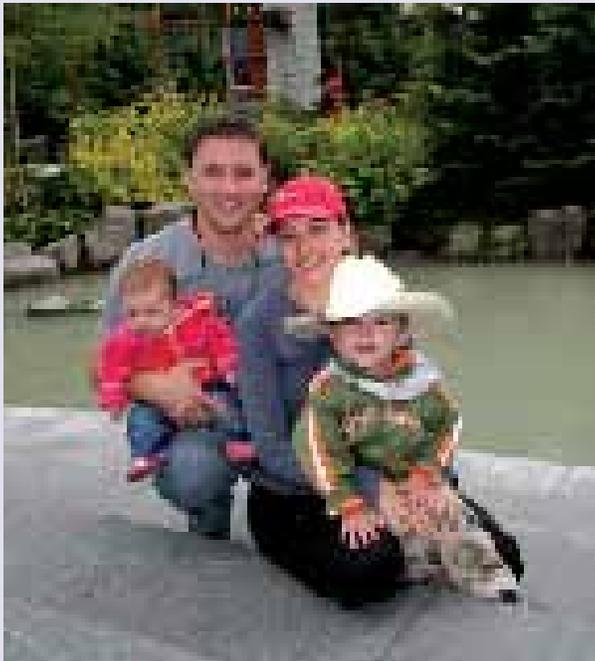
Beasley Family. Bradie age 5 (photo taken in 1980)



Bradie with dad and sisters December 2004



Bradie and Eric on their wedding day August 12, 2000



Bradie, Husband Eric, Son Ryker, and Daughter Bayden June 2006

At the age of one and every 6 months after I would return to Denver Children's to be followed in the Pediatric Pulmonary Clinic. Each time I would arrive they were more amazed that the child before them appeared so healthy. They would say to my parents, 'continue doing whatever you are doing. We cannot believe she looks so healthy'. Around the age of two the doctors stopped focusing on my life ending and started believing that I may be a medical miracle in the making.

At the age of six the pulmonary team said that my good lung tissue appears to be pushing out the bad, but that I would never experience full lung capacity. They told my parents get her in sports and keep her active. The doctors began to believe that I may not have any underlying problems at all due to my so-called congenital lung disease.

My entire life I have rarely worried about my lung condition. I have a sense of calm and a feeling that says it just is not going to be a factor in my life. Simply stated this "lung condition" of mine is not a part of my life. In some strange sense my struggles as a baby may have been presented as a purpose and reason towards my parent's life, not mine. A means to build on their purpose and trials.

I live with physical scars. A massive scar across my back and left side, where they opened me and where a chest tube was placed. I never see these scars when I look in the mirror, I am only reminded of them when a friend or stranger asks, "What happened to your back"? In fact, I do not recall a time when I felt insecure about someone seeing my scar (even in my high school prom dress).

I love to be active and athletic. I have a healthy competitive nature to me. Growing up I enjoyed swimming competitively, basketball, volleyball and track. At the age of 27 I ran my first sprint triathlon. I think that I conquered more of a fear than the question of ability to achieve a goal such as a triathlon. I certainly was not first but I felt amazed that I was able to end the race right in the middle of all the competitors.

I do recognize that I have certain physical limitations that I wonder at times are more mental than physical. I just do not allow myself to use my lungs as an excuse and always strive to work towards physical goals.

At the age of 30, I am a mother of two beautiful children (Ryker 2 years old, Bayden 4 months) and wife to the most amazing man. I was told on more than one occasion that it would not be wise for me to have children and even recall some saying I may not be able to. Like everything else surrounding my illness I took it as speculation.

I have always had a good gut instinct. That inner voice within me has a strong sense of right and wrong. No matter how big or small of a decision to make, I trust my gut!

I cannot help but credit my lung disorder for helping shape this within myself. So, as for my fear of becoming a mother, my gut told me I would have children and with that answer I never questioned or doubted. I do believe my strong sense of self was built into me for a reason and has been a guiding light for me throughout the toughest times of my life.

As I am writing this very moment my 4 month old daughter and two year old son are sweetly napping. I look at my 4 month old and realize I was her exact size when faced with a life threatening disease and invasive surgery. As a mother, I cannot help, but again, reflect upon how my mother must have felt. There are many days that I struggle managing a home and two healthy children. She had a sick child, toddler, preschooler and home to manage. The most difficult part to my story is that I am unable to ask my mother just how she felt about this time in her life... in hopes of gaining knowledge and perspective to put towards my own life. You may have wondered throughout my story why it was only told through the eyes of my father. Unfortunately, my mother's life was tragically taken in a car accident when I was eight years of age. I happily daydream and conclude that she was a devoted mother who did everything in her power to save my life. She wrapped her loving arms around me and protected me. I weep with tears knowing that as a mother she must have lived many days in anguish and fear for my life. Knowing she must have been feeling helpless and humbled by all that she faced. Given that she has been gone for the majority of my life and that my memory of her is faint, my childhood illness has given me a bond and connection with my mother that is strong at heart. I feel a sense of strength for my own life through hers. In my heart and based upon my faith I believe that one day I will be able to ask her myself to tell my story through her own eyes.

As for my father, he has helped shape who I am today. His loving hands and firm convictions have helped me define myself as a daughter, friend, wife and mother. His simple manner in which he operates in the world is an example to live by. He has taught me practical wisdom that has become my foundation for thinking and communicating. He is an outstanding citizen and loving man. I am so thankful he has been such a big part of my life.

I have had several points in my life where I have "bounced". Though I have little memory of my childhood illness I know on some level it has been one of the biggest bounces of my life. Because of it I am determined and live with less fear. I have a strong desire to live each day to the fullest. I tell my children and husband every day that I love them more than life itself. At several points throughout each day I stop and reflect on the gratitude I feel for that moment I am living in.



Bradie with daughter Bayden. Bayden is 3 months old. Near the same age I was when I had surgery.



Bradie's children Ryker and Bayden and family dog Danny.



There is magic in touch



Bounce means giving of yourself



I wait with excitement for the next "bounce"

I have learned so much from applying my journey to today. One of the best choices I have made was to gain professional and clinical skills working with children and families in the hospital setting. As a Child Life Specialist by training, I work with the emotional and developmental needs of children. My desire to work with children in the hospital did not come from a need to heal or change me. I do not recall one time in my clinical work when I referred to my own medical experience as a reference. Rather, it was a desire to give and comfort others during a traumatic time. No doubt my parents could have used a professional such as this. I am drawn to helping others in the hospital setting. I am certain that my environment and experience as a young baby planted this seed but I still have no memory connecting this. I was guided to my profession by inspiration and prompting. My ability to help families is directly related to my belief system and a greater understanding of life. To me there is something much bigger than this small stop in life. Through working with families in the hospital and being a part of some of their most vulnerable moments I feel blessed. I try to imagine that on some level I am like an angel in the life of a parent or child giving guidance, hope and friendship through a very scary time. As hard as I try it seems impossible to give back the wisdom each family has given me.

My life's work and purpose are being lived and discovered. From my professional work helping children and families in the hospital setting to being a mother, friend and wife, my work has just begun. Each day I try and stay open to that in which I am supposed to do in my life. I understand the bigger picture of life and wait for the next "bounce" with excitement that it is going to make me a better, stronger force in this world.

Each time I have bounced back from a trial in my life I feel stronger and more grateful. I grew up very young and have always felt like a wise soul in my body. I often tell my husband the day my mother died I became a grown-up trapped in a child's body. I would never change the course of my life because each defining moment has shaped me for today. I feel healthy in mind, body and spirit and feel that my life is full of abundance.

Lana's Story

TE Fistula

LANA STAHELI, PH.D. IS A COACH ON INTERPERSONAL RELATIONSHIPS AND LIFE STRATEGIES. SHE HAS HAD A SUCCESSFUL PRIVATE COUNSELING AND CONSULTING PRACTICE FOR OVER 30 YEARS.

DR. STAHELI IS AUTHOR OF SEVERAL RELATIONSHIP BOOKS. HER BOOKS INCLUDE TRIANGLES, UNDERSTANDING, PREVENTING AND SURVIVING AN AFFAIR; AFFAIR-PROOF YOUR MARRIAGE AND THE COMPLETE IDIOT'S GUIDE TO AFFAIR-PROOF LOVE. SHE IS CURRENTLY WORKING ON THREE NEW BOOKS, BOUNCE, BE TRANSFORMED, AGAINST THE ODDS—CHILDREN FACING DEATH OR DISABILITY AND LIVING TO TELL ABOUT IT AND HIS WAY—MEN AND NARCISSISM.

SHE IS THE FOUNDER OF BOUNCE, BE TRANSFORMED

TO MY PARENTS, VERCIL AND MILDRED RIBBLE, WHOSE WISDOM,
LOVE AND GUIDANCE GAVE ME A JOYFUL LIFE.

I ALSO WANT TO GIVE SPECIAL THANKS TO DR. WILLIAM LEES,
DR. CAMERON HAIGHT AND THE STAFF AT THE UNIVERSITY OF
MICHIGAN IN THE LATE 1940'S.





They wrote letters to one another while Vercil was in the Navy and Mildred worked at Eaton's Manufacturing. Vercil came home on shore leave and they married a week or so after seeing one another for the first time.



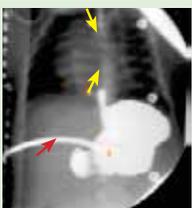
Mildred Sponseller and Vercil Ribble married in 1944.



Mildred and Lana, 1947. My survival was doubtful.



A TRACHEOESOPHAGEAL FISTULA IS A BIRTH DEFECT THAT HAS AN OPENING BETWEEN THE TRACHEA (BREATHING TUBE) AND THE ESOPHAGUS (SWALLOWING TUBE). SALIVA AND GASTRIC SECRETIONS GET INTO THE LUNGS CAUSING THE BABY TO SUFFOCATE.



THIS X-RAY SHOWS THE ESOPHAGUS ENDING BEFORE REACHING THE STOMACH (BETWEEN YELLOW ARROWS). THE TUBE (RED ARROW) IS INSERTED DIRECTLY INTO THE STOMACH (GASTROSTOMY) TO FEED THE BABY.

syndrome—a group of signs and symptoms that together are characteristic or indicative of a specific disease or other disorder

I am writing and editing *Against the Odds, Children Surviving Death or Disability and Living to tell about it*, as a tribute to my mother and father, Mildred and Vercil Ribble, and as a way of recognizing the many gifts from all of those in the health care community who care for children.

Mildred Sponseller and Vercil Ribble, my mother and father, were married in September of 1944. They and my mother's sister and brother-in-law, Thelma and Bob Lake, who lived two houses away, were expecting their first babies in June of 1947. These babies would be the first grandchildren of Dale and Lucille Sponseller.

On June 9th, Aunt Thelma and Uncle Bob's baby girl, Marcia, was born. She was a plump and healthy little girl. Less than two weeks later, June 21, 1947, I was born, weighing 6 pounds and 12 ounces, but my mother's obstetrician, Dr. Munger, realized something was wrong.

On June 24th, I was admitted to the University of Michigan, Department of Pediatrics. Dr. Munger had made the correct diagnosis of tracheoesophageal fistula, or TEF. TEF is an opening between the swallowing tube (esophagus) and the windpipe (trachea) that allows anything swallowed to seep into the lungs. Plus, my esophagus came to an abrupt end. Most babies died from pneumonia.

On June 25th, my first surgery to create a passage from my mouth to my stomach was performed by Drs. Cameron Haight and William Lees. The next day a gastrostomy was performed to put a feeding tube directly into my stomach.

Dr. Cameron Haight at the University of Michigan was the first surgeon to develop a way of closing the windpipe and feeding the baby through its esophagus. Prior to 1945, TEF was usually fatal. One reason for the high death rate is that most babies born with TEF also have other birth defects, now referred to as the VACTER Syndrome: V-Vertebral defects, A-Anal atresia, C-cardiac (heart), T-E -Tracheo-Esophageal fistula, R-Radial and Renal abnormality. Babies with TEF usually have at least 3 of these abnormalities

My survival chances seemed good immediately after the surgery. I was a full term baby with a good birth weight and I had the good fortune to be in the best hospital in the world for treating TEF. The University of Michigan was among the first hospitals to create special training in thoracic (chest) surgery. Along with specially trained surgeons was a pediatric staff that was trained to care for babies with life threatening birth defects.

My post-operative recovery was excellent.

In order for me to eat normally as I matured, my esophagus was stretched and dilated. A “string” with a small soft rubber bulb on one end was placed inside my esophagus so it could be pulled up and down from my mouth through my esophagus out of the hole in my stomach. This simple procedure for dilating and stretching would continue until my esophagus was big enough for swallowing enough milk to support my life. Esophageal dilations were performed throughout the days that followed, until my esophagus was considered adequate and significant oral feedings were started.

I was three weeks old when my parents were told I was not doing well. The doctor writes, “The baby became so choked up with mucous that she had difficulty swallowing...because of all the mucous in the baby’s pharynx, it is suspected that a tracheoesophageal leak might still be present”.

During the days and week that followed, my survival was uncertain. Dr. Hewitt, my pediatrician writes: “The baby received 30,000 units of penicillin every three hours, intramuscularly (shots) for the first 22 days of her hospitalization.” Finally, the leak stopped. Again, I was fortunate to be in a university hospital noted for its research and pioneering treatments, because antibiotics were not widely available until the 1950’s, and that would have been too late for me.

Visiting hours were limited in 1947, but because of the uncertainty of my survival my parents were allowed to visit me whenever they could. My mother says they came to Ann Arbor every weekend, and weekdays, when they could. My dad was a lineman for Consumer’s Power Company and in this era there were no family leave or parent rooms for staying overnight at the hospital. Every weekend they drove the 60 miles from Ceresco, where they lived, to Ann Arbor. The 120 mile round trip drive to and from the hospital at 30 or 40 miles an hour was a long day. Staying in a hotel was too expensive. I can only imagine the fear and heartache my parents must have felt each time they left me at the hospital and went home wondering if they should put away the baby bed, baby clothes, baby blankets and toys. Each time they came and left not knowing if they would see me alive again, but the doctors were encouraging, reminding them that I was a strong willed little girl.

I was 3 months old and had spent all of my life in the hospital when Dr. Hewitt writes, “We will send Lana home with her mother for a trial, but she will return to the hospital for on-going dilation twice a week”. Finally, on September 20th, my mother and father took their baby home in “good condition” weighing 8 pounds 15 ounces.

VACTER SYNDROME IS AN ACRONYM USED TO DESCRIBE A SERIES OF CHARACTERISTICS WHICH HAVE BEEN FOUND TO OCCUR TOGETHER.

V STANDS FOR VERTEBRAE, THE RIBS AND SPINE ARE OFTEN MISSHAPEN
A STANDS FOR AN ANUS THAT DOES NOT OPEN TO THE OUTSIDE OF THE BODY

C REFERS TO CARDIAC (HEART) DEFECTS.

TE STANDS FOR TRACHEOESOPHAGEAL FISTULA, A HOLE BETWEEN THE TRACHEA (THE WINDPIPE) AND THE ESOPHAGUS (THE FEEDING TUBE).

R STANDS FOR RENAL (KIDNEY) AND RADIAL (ARM) DEFORMITIES.



Baby Lana Sue Ribble

IN 1941 CAMERON HAIGHT OF MICHIGAN SUCCESSFULLY REPAIRED ESOPHAGEAL ATRESIA IN A 12-DAY-OLD BABY BY USING A PRIMARY-STAGE LEFT-SIDED EXTRA PLEURAL APPROACH. HE MADE SEVERAL OTHER ATTEMPTS BUT MOST BABIES STILL DIED. HE WAS A PIONEER IN ACHIEVING LONG-TERM SURVIVAL WITH A WORKING ESOPHAGUS. THE SPECIALTY OF THORACIC SURGERY STARTED AFTER WWII.



Cameron Haight, M.D.
1901-1970

In the 1940’s, most homes had a single telephone, and most were on party lines. Party lines meant that several homes would share the same line. The phone would have a different sounding ring for each house, but when anyone on the party line received a call the phone rang at everyone’s home on that line. It must have been trying for my parents each time the phone rang, wondering if this would be the call they most dreaded.



Model A Ford



Marcia & Lana



Mildred & Lana

Back and forth to the University of Michigan was an all day event in 1947. I was three months old when I went home for the first time.



Drs. Lees and Haight were finally asked to surgically reinsert the string, but by then my esophagus was so swollen that their next four surgical attempts were unsuccessful. The greatest risk I faced was the ether anesthesia. Ether was not scientifically measured, but dripped onto gauze and placed over the face. Anesthesia continues to be the biggest risk in surgery for children.



Appreciating all the doctors had done for me, then knowing that their baby was again fighting to stay alive because of a resident doctors' mistake must have been overwhelming.

Res-i-den-cy n

a period of specialized training in clinical medicine or surgery in a hospital on completion of an internship.

May 10, 1948

Dear Mrs. Ribble,

Thank you very much indeed for the very fine colored photograph of Lana which I received after my return to Ann Arbor recently. We all think that Lana looks grand and I was delighted to hear that she is doing so well.

The opinion has been expressed that perhaps I received the picture for Mother's Day, but while I can honestly say I have a block of stock in Lana, I can't honestly state that I could be her mother. I will be extremely grateful to you if from time to time you will write me and let me know Lana Sue is coming along. In the event that you have no difficulty, I do not feel it is necessary for you to make the trip to Ann Arbor to see us, unless you happen to be in this neighborhood. We will, of course, be delighted to see you and Lana at any time you feel it advisable. Please do not hesitate to write me if I can be of any assistance to you.

Again, with many thanks for your kindness, and with personal regards to you, your husband and of course to little Lana.

Sincerely yours,
William M. Lees, M.D.

There would be long drives back and forth to Ann Arbor twice a week, but the worst was over. The doctors assured my mother and dad that I was healthy and normal. The pain and heartache of being away from their baby was coming to an end. My mother was able to join her sister with their new babies as they had planned so many months before. My baby cousin, Marcia, weighed 14 pounds compared to my 8.15 but that didn't matter. I was healthy and happy. I was greeted by my grandmother and granddad, aunts and uncles all relieved that my battle to live was over.

My family drove back and forth to Ann Arbor twice each week and for the first three weeks everything went as planned. On October 10, 1947, the medical records say, "Lana readmitted to the nursery. Progress had been reasonably satisfactory except that on the day of admission the string that extended from her stomach to her mouth became dislodged".

"On the evening of admission, the string was replaced and we planned to discharge the baby the following morning. The next morning the child's temperature was 102.6." As it turned out, I only had an ear infection and I went home five days later. My parents breathed a sigh of relief. They had lived on an emotional roller coaster for four long months. Finally, baby Lana was healthy enough to fight the usual childhood illnesses, so home we went.

I had been out of the hospital 20 days but after being back home only 2 more days, my mother and father brought me back to Ann Arbor. The medical records show, "Baby Lana was first admitted to the Pediatric Department of the University." The pediatricians tried repeatedly to re-insert the string that one of their residents had broken. It was another four days before my surgeons were informed. Drs. Cameron Haight and William Lees operated and found excessive swelling caused from trauma from all the previous attempts. My parents went home and I stayed at the hospital. Every time the telephone rang, they held their breath, fearing that my struggle was over.

More children died from the anesthesia than from the actual surgical procedure, a fact that remains true today. In the 1940's, ether was the anesthesia commonly used. It was very difficult to give to children because there were no guidelines to determine how much to give and it was hard to monitor a baby's absorption rate. Because of that increased risk, some of the doctor's attempts to reinsert the string were done without anesthesia. These repeated attempts were costly to a four-month-old baby. The records show that on October 27th, I stopped breathing. Drs. Haight and Lees were reluctant to use ether again, but decided to try once more to reinsert the string on November 7th, and again they failed. All the attempts had failed and I was no longer strong enough to rebound.

Each weekend my parents drove from Battle Creek to Ann Arbor to see their baby and each Sunday they went home not knowing if I would be alive the next weekend.

It was clear that I was losing ground, my weight had dropped from 10 pounds in late September to 7 pounds in late October. As a final effort, Drs. Haight and Lees decided to start over. It was my last chance and it was a big operation that no one had tried on a baby.

I survived the surgery, but I was now in “very poor condition.” A day after Drs. Haight and Lees re-operated, my right lung began to collapse. The x-ray showed a leak between the trachea, the esophagus, the skin and the right lung. The radiologists confirmed that I had pneumonia plus a wound infection. My right lung collapsed completely, another surgery had to be done. An opening was made into my lung and the lung walls were scraped, “yielding copious amounts of mucopurulent, thick, yellow, non-odorous pus”. I had been on large doses of penicillin for months, and now it was ineffective.

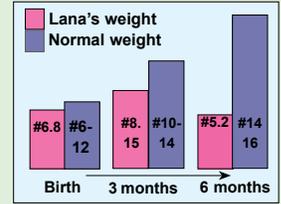
My parents were told that as a last resort a new antibiotic, streptomycin, could be used, but it had never been used on an infant. Dr. Lees explained, “This antibiotic is known to cause deafness but I don’t know what else we can do.” My mother and father signed the consent. I was six months old and weighed five pounds. Once again, they went home without their baby.

Twelve days later, the first signs of success began to appear. The records say, “The abnormal density of the right lung is somewhat decreased.” It is January 8th when the records show “evidence of passage of material through the esophagus to the stomach”. In the days and weeks that followed the pneumonia and the skin infection subsided and I began to take fluids by mouth. On February 16, 1948, at seven months old, weighing less than ten pounds, I went home.

I was back in the hospital a few months later, but only briefly and that became the pattern for the next few years. I would have difficulty swallowing and would have to return but only for a few days at a time.



There were many more sleepless nights and worries for my parents but the worst was over. Of course, they didn’t know that. Both my mother and father were thoughtful, loving and wise. They never seemed worried about me and they enjoyed me. I had a fun, happy childhood, a gift not all children receive when they have been sick. Too much treatment and too much worry can bring an early end to childhood.



It is hard to imagine that a six month old baby could weigh as little as five pounds and survive to live a normal life. My mother recalls Dr. Lees telling her, “Lana Sue is a fighter and I will fight along with her.” These letters show his determination and devotion during the winter of 1947. I believe Dr. Lees’ attention and affection helped save my life.

March 21, 1949

Thank you...I realize that chopped foods might cause Lana to cough...Place her on strained food that is normally prepared for the rest of the family.

I have every reason to believe that she will be a perfectly normal child and in my opinion she can live to be 100 and die in an airplane accident. The fact that she wants her mother close should not disturb you because we must realize that for the greater part of the first year of her life she remained in a hospital where although we try to give the children tender, loving care, it is not like being at home with Mommy. Having gone through several major procedures I believe that it would be psychologically best for you to give her as much as it's physically possible for you to give....

***Sincerely,
William Lees. M.D.***

January 14, 1949

Your letter of January 6th was received and because of my recent illness, I have not had the opportunity of replying earlier....

I was unaware of the fact that you were still feeding her entirely strained foods. I believe she is perfectly capable of chewing and swallowing chopped foods, but in as much as she has not had any experience with these foods, I would give them slowly....

I sincerely believe that from now on we must treat Lana as though she were, entirely normal child which she apparently appears to be. I, too, was delighted to hear that your Christmas this past year was so wonderful. I can recall distinctly spending a good share of last Christmas with Lana here at the hospital.

***Sincerely,
Dr. William Lees***



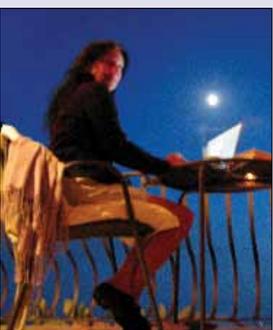
I think of my childhood as happy, fun and normal. I assumed other kids swallowed the eyes of their toys and put everything they could find in their mouths. I did know that those kids didn't have to go to the hospital to have it removed. My many trips back and forth to the hospital were normal for me.



My parents were flexible about what I ate. I didn't like breakfast foods, so I ate foods that were easy to swallow, and as it turns out full of antioxidants.



My gastroenterologist was trying to persuade me to have my esophagus dilated when he said, "Lana, wouldn't you like to be able sit down and have a nice juicy steak and glass of red wine?" I sighed with relief and answered, "No, I am happy with white wine, cheeses, fruits, fish and pasta," thinking I might not need the dilation! I still had the dilation and I can have steak but I don't usually think it is worth the extra effort that I need to use to eat it.



Perhaps because of spending time waiting for doctors, I learned to bring something to read or a game to play. I also learned to observe the scene around me and look for beauty; it was a way to calm myself at the doctor's office.

Lana writing in Positano, Italy

I had many more trips to the hospital because I was unable to swallow something I ate, that included my panda bears' eye and some of my dad's spare change. But, mostly it was food like hot dogs or white meat of chicken, carrots, celery and other foods that are not slippery.

I have several defects associated with the VACTER Syndrome. V is for vertebral abnormalities. My rib cage is unusually narrow and several of my ribs are fused, making my lung capacity about 70% of normal. The small capacity makes it more difficult for me to breathe, especially in higher altitudes or hiking uphill. But, if I pace myself I can go anywhere I want. For many years, I got pneumonia every winter. I have spinal scoliosis (curved spine) that sometimes gives me back pain, but, of course, everyone has some back pain sooner or later. When my back hurts I take ibuprofen every four hours, walk for exercise and ignore it.

C is for cardiac (heart). I had a heart murmur for many years and took antibiotics before having dental work, but that is now proven to be unnecessary. As an adult, I developed atrial fibrillation, which is an inefficient and irregular heartbeat. I regulate my heartbeat with medication and exercise.

T is for tracheoesophageal and my esophagus is very small about 1/4 the normal size and has a narrowing slightly above the opening of into my stomach. It is at this narrowing that objects get stuck and have to be surgically removed. I prefer to eat early in the day rather than in the evening because it is easier for me to swallow when I am not tired. Food is not important to me, but I consider that a good problem, because it makes it easier for me not to gain weight. Milk and red wine are also hard for me to swallow. So, I drink white wine and take calcium. In recent years I have to have my esophagus dilated every couple of years.

R is for renal (kidney). In my 50's, I developed very high blood pressure, and I don't know if that is related to the VACTER syndrome or family history. It is controlled with medication, relaxation techniques, exercise and a puppy.

As I write this list, I think that person sounds sickly, but I am not. I am quite matter of fact about these issues because I don't have any life experience without them, so for me they are normal and they do not prevent me from doing whatever I want.

In addition to the wonderful medical care I received, I am also grateful for the medical treatments I did not receive. Many children receive so many treatments throughout their childhood that they begin to think of themselves as defective, and dependent—this problem is called the Vulnerable Child Syndrome.

This is one of the reasons for creating this booklet—it's so important to focus on what is right with each of us, not what is wrong.

Because childhood seems to play a particularly significant role in how we think of ourselves and how we think of those around us when we are adults. We often bring forward lessons from childhood and replay those lessons over and over in our minds believing that these memories are true and valuable. Sometimes they are freeing and other times they are limiting, but memories and the lessons we take from them can be changed.

Regardless of our intellectual understanding of ourselves, our emotions are powerful and ever present. Suppressing emotions does not make them go away and neither does dwelling on them. Finding the balance between feelings and thoughts is important for health and healing.

Our brain is hard wired to keep us alive first and foremost, this instinct has been honed through millions of years. We are not going to be able to change that, but we can learn to manage emotional energy.

Human beings can choose what we think about and how we think about it. It is this ability to change our minds and our emotions that makes us unique on earth. This human ability to change our thoughts and our feelings is called emotional intelligence.

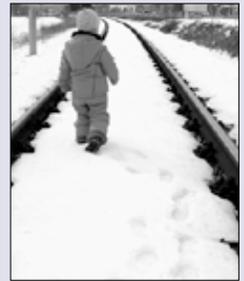
Our recollections are so fast and so repetitive that they often seem automatic and therefore right. But, one way of viewing yourself and others is as “right” as another. It does not matter what the reality of the experience was, it is our interpretation of the memory that determines how we feel. We can choose to remember people or events as good or bad, dramatic or funny. Whether we choose happy thoughts and feelings, or unhappy thoughts and feelings determines our physical health and our ability to heal, physically and emotionally.

I have added my dad's memories along with my perspective (right). Unhappy recall of childhood experiences leads to ill health. My dad dropped out of school after 9th grade and joined the Navy when he was 16. He worked for the same company, Consumer's Power, for 35 years. He died when he was 64. In recent years, studies have shown that happy people are deliberate about making themselves happy. Making yourself happy takes discipline and practice. We can control what we think, and that changes our feelings and our health.

My father's mother, my Grandma Marie Dunkin, was French Canadian. She had one daughter, Vivian, before divorcing her first husband. She then married Vercil Ribble and had two sons, Vercil and Bob. Vercil, Sr. died at age 29 from TB. She then married Bob Keefer, my father's hated step-father.



My father's memories of his childhood included walking miles and miles to school in the knee deep snow, a story that was supposed to make us grateful for what we had—a ride to school by bus. That story did not make much of an impression, but two other stories from his memory did make lasting impressions.



My dad told of begging his step-father to let him take his brother, Bob, to the doctor, but he wouldn't and Bob died. My dad was never able to put this memory behind him. A doctor visit would probably not have saved Bob, because there were no antibiotics or other treatments that were effective against pneumonia.



The other story deeply rooted in my memory is of my dad being “tied to the clothesline like a dog” (with a rope wrapped around his neck—that was my interpretation). As an adult, I suspect the rope was around his waist, since that was a common way of keeping track of your children. He remembered his childhood as unhappy and his memories reflected that emotion.

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