

The Legacy

Presented By Barbara Byer – October 27, 2009

Thank you for being here today. My views on motherhood and Amyotrophic Lateral Sclerosis at first might seem disparate but do have meaningful connections for me and hopefully for all of you as well.

As the mother of five children, I envisioned them becoming fulfilled, productive adults who would realize their dreams. I hoped that our parent child relationship would shift into a peer relationship, one that would contain mutual support and care for each other.

As a child development specialist, I've been fascinated by human behavior, character and temperament. What makes one person stand up in the face of overwhelming odds and another succumb to the devastation. What makes one group of siblings band together and another choose such separate and distant lives that communication between them becomes non-existent. What makes one family turn away when one of them is confronted with a fatal illness and another pull together. I wish I had definitive answers for you today but these are issues that confound brilliant psychiatrists and talented sociologists. What I can offer is a personal perspective and experience that I hope will provide some insight into these huge questions.

Our five children are very different from one another. Matthew is the professional, analytical, conservative, financial whiz. As a child, he spent most of his time reading, taking apart appliances, and collecting wires and transistor parts. We called Josh Clarabelle the Clown for his antics, although today he's a serious IT man and a former marine major. Then there's Ben. We joked when he was a pre-schooler that we could take him deep into the forest, check his pockets for breadcrumbs and pebbles and he'd still find his way home. Sarah is the caring, supportive one who rarely argued, the good girl who put herself to bed when she was tired. Rebeccah, the youngest, is probably the toughest one of the bunch, head strong, determined, and opinionated, a composite of both her parents and with 3 older brothers, she learned early on not to back down.

You can imagine a household of five children seven years apart in age was challenging. Then as now, I believed my job was to help each of them find their strengths and to encourage cooperation between them. I tried not to impose specific expectations. Rather, I encouraged them to do the best they could with whatever they pursued. And to pick things they really enjoyed which is why they all graduated from college with majors in various aspects of liberal studies. Not a practical one among them but they were happy and eventually found ways to make a living.

Encouraging cooperation began early. My rules included no hitting which was sometimes ignored. But all arguments, at least those I was privy to, were settled in a neutral spot with no distractions. I waited outside the closed door until a settlement had been reached which sometimes happened because they were hungry or tired of looking at each other. The one rule I tried never to break was taking sides, my singular defense against sibling rivalry. Even

if I saw one of them throw the first punch, how did I know that a kick under the table the day before didn't precede it? More than anything, I wanted these five children to become friends who would support and care for each other for the duration.

It was in this environment that our children grew to adulthood and moved on into their own lives. As they married and began to have children of their own, I pined for an adventure, away from our life as art dealers. In 2000, my husband Steve and I moved to a hundred acres in Dodgeville to experience the country life. I saved my sanity by taking on the role of Director of the Family Resource Center in Iowa County while Steve mastered the art of driving a tractor and clearing brush.

Just as life relaxed a bit for us, ALS, Amyotrophic Lateral Sclerosis, known also as Lou Gehrig's disease, struck our son Ben. Symptoms began to appear as early as 2000 but we thought it was carpal tunnel or that he had strained his voice rehearsing for a play. At 31, Ben's life was in full gear, newly married and the father of 2 year old John. His career as a playwright and actor was burgeoning. Ironically, the firm ALS diagnosis in 2002 coincided with Ben's starring role in Lee Hall's play 'Cooking with Elvis'. Brilliant monologues and songs were interrupted by whole scenes of Ben comatose in a wheelchair, the result of his character's fictional car crash years earlier. I saw the play 4 times, believing it would be his last. But Ben was the golden boy for whom things always worked out. Somehow, we believed even in the depths of our despair, he would be the lone survivor. On all counts, we were wrong.

Steve threw himself into research in a desperate search to save our son's life. Google made possible exploration never dreamed of just a few years earlier. With a sense of urgency at his back, Steve researched scientific data on his computer 20 hours a day in hopes of finding a relevant therapy. He posted on neurological forums, tirelessly wrote and called neurologists, researchers, pharmaceutical manufacturers, scientists, stem cell clinics and patients. Today, Steve has emerged as one of the most knowledgeable persons on the planet about ALS.

ALS strikes terror because it affects all the voluntary muscles in the body, gradually sucking the life out of every capacity to live as human beings. Patients are told by their neurologists that death within 2 to 4 years is inevitable. Think of a tree, how it stands still and can move only when the wind stirs its boughs. It grows, takes in nourishment through its roots, sheds leaves but is completely powerless otherwise. So it is with ALS. Eventually all a person can do is move their eyelids. But, unlike a tree, an ALS victim can think, feel and understand everything with clarity, a living hell.

In the 150 years since it was identified by Jean-Martin Charcot, little to nothing has been developed to combat ALS nor has the cause been identified. Under this cloud, Steve quickly became known on the forums as a bright guy who was a committed researcher. Patients began emailing him privately, to ask advice about any supplements Ben was taking and current research he'd unearthed. Eight months post diagnosis, Steve found a Chinese concoction called BuNaoGao in an obscure online posting by a PhD in Boston. Fourteen herbs consisting of various twigs, berries, turtle shell, and bone had been developed by a

Chinese neurologist and tested on a small group of ALS patients with some measureable success in slowing progression.

By then, Ben was living with his sister Rebeccah, his marriage having fallen victim, as do so many, to the rigors of ALS. We ordered a 3 month supply of BuNaoGao and handed over what looked like bags of spring landscape cleanup to Rebeccah who cooked the contents up into a brown goey liquid that Ben drank daily.

After six weeks, Ben felt that his voice was a little better and his energy increased, which in the world of ALS is pretty good.

“Mom,” he said, “I’m going to make a film.”

For the first time in months, he seemed a little upbeat.

“Great!” I said. “What about?”

“ALS,” he said.

Ben’s resilience and tenacity, such an integral part of his temperament, had surfaced. I wasn’t surprised. Even though I’d no idea if he actually knew how to produce a film or where the money would come from or whether he possessed the talent or technical capability to make a film, I suspected he would succeed.

When he was five years old, he waved me away and taught himself to ride a two wheeler, focused each afternoon until he could start, stop, balance, turn and ride with his older brothers. At twelve, he talked a cab driver into taking him to Dominick’s Grocery Store so he could purchase a year pass to Great America amusement park, then convinced the driver to wait while he collected the fare from a friend waiting for him at the train station. Add to that Ben’s creativity, talent and intelligence. Of course he’d find a way to create a ground breaking, world renowned film. I, along with so many others, also believed just as deeply that Ben, of all people, would be the first one to survive ALS.

Ben’s childhood friend Roko Belic, an award winning cinematographer in his own right, loaned Ben his equipment and talent. Together, Ben and sister Rebeccah, his producer, created ALS Film Fund, a web site and began to raise funds. My 60th birthday in the summer of 2003 was a bittersweet affair that Ben captured on film. That autumn, he and his Dad traveled to the east coast to interview US patients Steve had met via the internet. In December 2003, Ben, John, Stephen, Roko and I flew to Samos, an island in Greece, to visit and film the Annie and Tony Papoulias family, one of many ALS families that Steve had come to know through the internet. Annie at forty five was considerably more advanced than Ben, but hers was a future we still believed could be averted. We still had time.

The summer of 2004 Ben, together with his film entourage, flew to China where he not only filmed Dr. Yong Chou Xia, the creator of BNG, but found the title for his film which he named, ‘Indestructible’. A few weeks later, the group arrived in Beijing where Steve and Ben discovered an experimental fetal cell therapy. Ben convinced the neurologist to operate on him and also allow filming of the surgery. An amazing feat considering the language barriers and the long list of patients preceding Ben who had requested the surgery. But, a few months after their return, all of our high hopes ended with discouraging results.

In 2005, Ben and Roko flew to Israel where they met Ben's older brother Josh who was then posted to Eritria in Africa for the United Nations. As the disease ravaged Ben's body, he sought not only the elusive cure, but also meaning for his life. In this final segment of 'Indestructible', Rabbi Daniel Gordis offers compelling philosophical insight while Joshua shares his perspective of our family's challenges in the face of ALS. When Ben wasn't traveling, he was editing more than four hundred hours of film and writing compelling essays for his blog about ALS, his life, vision and hopes while also parenting John.

While Steve searched for a cure and Ben and Rebecca filmed, I focused on ways to make Ben's life easier in practical ways by sewing loops on zippers and cooking foods he could chew easily and enjoy. Rebecca's marriage to Drew in 2004 and the birth of their first child, Henry, in 2006 called for change. When Ben moved into his own condominium, the search for a competent caregiver began. In between the many interviews and trial runs, I picked up the slack until one wonderful day, Elizabeth, an extraordinary caregiver, appeared who gave Ben devotion and care throughout his final years.

As Ben lost complete control of his hands and arms, he switched to operating his computer with his toes. When that was no longer possible, he switched to an eye response computer which enabled him to edit "Indestructible", send emails and search the web more easily. As his voice weakened, he used the speak button to verbalize whatever he wanted to say. Confined to a wheelchair, Ben shifted his creative energy into writing blogs for the ALS Film Fund website where they remain accessible to this day.

On one of my many day trips into Chicago to see Ben, I told him how insightful, profound and beautifully written I thought his essays were and how impressed I was that he was able to write so well without editing. "I edit", he said and rolled his eyes at me as if to say, only a mother would think that.

In 2007, "Indestructible" was accepted into the world renowned film festival Cinquest, located in San Jose, California. Family, friends, and other patients, were there to support Ben, who by then, was confined to a wheelchair. More than a thousand people filled the theater on award night. When 'Indestructible' was given the Best Documentary Award, the entire audience rose to give Ben a standing ovation. I was delirious.

After a celebratory dinner, Steve and I collected the grandchildren to take them back to the hotel. As I watched my five children move down the sidewalk, Ben in his wheelchair, to enjoy an evening out together, it struck me that this is what I had most hoped for those many years ago, that in the good times and the most difficult of times, our children would band together in support, love and care.

"Indestructible" has since been in dozens of film festivals throughout the world, viewed by thousands, has won many Best Documentary awards and appeared in several theaters. One of the many events was right here at the Waisman Center where screenings were hosted during January 2008. Another was the Wisconsin Film Festival that spring where Sarah was

onstage with Ben, fielding questions from the audience and translating Ben's answers for the viewers.

"Indestructible" ends 2 ½ years before Ben's death on July 3, 2008 but he never stopped filming himself and others, working to inform and educate right up to the very day of his death. I'd like to show you now, a brief preview of "Indestructible."

(Preview of 2 ½ minute trailer)

ALS does not discriminate. Anyone sitting here today can become afflicted. Ask 10 people and 2 know someone in their lives who suffered from ALS. The myth that ALS is an old man's disease or an orphan disease is false. The actual average age at onset is 40. Men and women are both susceptible. 5000 to 7000 people are diagnosed each year in the US, the same number as are diagnosed with Multiple Sclerosis. The difference is that those with MS live and number 500,000 while those with ALS die and number only 35,000. Until we know what the root cause is, no one is safe. Nothing will change until public awareness is heightened. The comparison between studies currently funded for research is stunning. Multiple Sclerosis – 472 studies; Huntington's disease – 581; Alzheimer's – 692 research projects; Parkinson's – 614; AIDS – 4213. And ALS? A mere 130 research studies at this time.

What's needed is more voices, yours and mine, bringing ALS to the forefront of public awareness and governmental involvement in research.

One very important action that I'd like you to consider is purchasing a copy of "Indestructible". Of course, I'm his mother so my telling you it's brilliant carries bias with it. But here are a few brief, more objective reviews.

Variety Magazine stated: "An intimate, lacerating, absorbing visual diary of the three-year onset of terminal disease Amyotrophic Lateral Sclerosis (ALS) in aspiring filmmaker Ben Byer." "Indestructible" is an immersive, edifying journey of acceptance, setback and strength."

The Chicago Tribune said . . . "Because of my passion for film art, the universe often clicks by 24 frames at a time. And within the interaction with the projected image, there are times when a film maker's soul touches mine, and can create new thoughts and energy for my own life. I was privileged to view a documentary film called Indestructible, and experienced through that screening a new definition for hope."

In The Academy of Neurology Journal . . . "The most compelling part of Ben's story is his philosophical quest to learn how to live in the face of approaching death. Ben's ultimate defiance of mortality is the making of this movie. I urge you to see it and experience its inspirational message."

Critic's Choice for Chicago Reader

"When Byer journeys to the top of Masada, the focus has shifted from fighting the disease to finding life's meaning, and the spiritual dimension lifts this stark, unsentimental video essay into the realm of art."

New City Chicago Magazine stated. .

Yes, it's a superhero movie, but not the one you'd expect. Beautiful and heartrending, "Indestructible" is unforgettable. From Byers' director's statement: "My initial purpose in making this film was to share the extraordinary moments, both dark and light, of a life with ALS. When we unlock the secrets of ALS we will better understand not only neuro-degeneration, but also aging, environment, psychology, spirituality, and what it truly means to be both alive and facing mortality every day."

And Willamette Week said. .

Byer illuminates the realities of this terrible fate while maintaining a don't-pity-me smile. Touching and emotionally jarring, Indestructible is a beautiful film that made me feel ugly for ever taking my health for granted. This film should be obligatory for anyone who knows anybody living with ALS. And for those who don't, still check it out. If you watch this film and don't tear up, find a psychiatrist—you're as broken on the inside as Byer is on the outside

Please watch 'Indestructible' with family and friends so that all of you can become informed. Each copy you purchase provides an ALS patient with a free copy. With 35,000 patients in the US, we've a long way to go before each patient has the experience of knowing they are not alone, there is hope, that a man they never knew maintained his humor, intelligence and faced his future with grace and dynamism, that they can choose a similar path.

The message to every ALS patient who walks into a neurologist's door today is the same as it's been for 150 years – you have 2 to 5 years, go home and get your papers in order, there is nothing I can do for you. Slow deterioration is your future. You will end up, if you choose to use a ventilator and a feeding tube, a thinking, feeling, loving, caring brain, unable to scratch an itch or drink a sip of water.

To combat this debilitating message, Steve and I began informally supporting ALS patients and their families in 2003, helping them navigate through the research, clinical tests, and information that flood the internet. Emails and telephone conversations from desperate patients and families never stopped. Each time a promising protocol or treatment surfaced, hundreds of patients sought Steve's advice and counsel which he gave freely. We traveled throughout the US and Europe, visiting patients we'd met online, offering encouragement and suggestions for ways they might improve the quality of their days.

"You need to formalize all this information or it will be lost." A friend chided us. Ben enthusiastically agreed. The result of that conversation is ALS WORLDWIDE, a not for profit organization Stephen and I established last year. Our mission states that we provide support to ALS families internationally through scientific research interpretation, individual patient advocacy and community activism. I invite you to support our efforts by visiting our website at www.alsworldwide.org , becoming fully informed and educating others.

At the current time, our organization is pursuing access to Iplex a growth hormone that has had some success in stimulating muscles, alleviating choking and improving swallowing mechanisms in ALS patients but has been taken off the market. The issue surrounding Iplex is a complicated story fully described on our website. Another effective procedure still mired

in FDA regulations is the diaphragm pacer, a mechanical device that stimulates the diaphragm to enhance breathing capabilities. A third is a surgical procedure that injects neuronal cells into the brain to replace deceased neurons. After 10 years of effort, Neuralstem, the creator, has just received FDA approval for proceeding with clinical trials.

Our travel to visit ALS patients and their families in their homes continues. Global Healthcare Initiatives are explored both in our website and through presentations Steve has provided to the World Stem Cell Summits sponsored by Genetics Policy Institute. We are currently pursuing a new FDA approach that includes an ALS fast tracked committee of young, talented physicians, surgeons and scientists who can act with both care and speed that incorporates all potential therapies. We support efforts by Tecnologico de Monterrey in Mexico where an autologous stem cell procedure shows promising results and is now available to international ALS patients.

ALS WORLDWIDE is committed to finding a cure in our lifetimes. Please join our efforts. When the mystery behind ALS is unlocked, powerful knowledge will be released that will inevitably lead to cures, not only for ALS, but for other crippling diseases like Parkinson's and Alzheimer's.

Lou Gehrig gave ALS a pronounceable name and a face for an obscure disease little understood. He was a great man who left his legacy on the baseball field with expressions of gratitude for his life, then disappeared from view.

Ben Byer was a little known playwright and burgeoning actor, who possessed the courage to bring ALS out of the shadows and place its debilitating and devastating aspects into the light. Faced with a brief future, Ben created a worthy legacy of bravery and hope.