

RIVER OF HOPE

My Journey with Kathy **in Search of Healing from Lou Gehrig's Disease**

David Tank



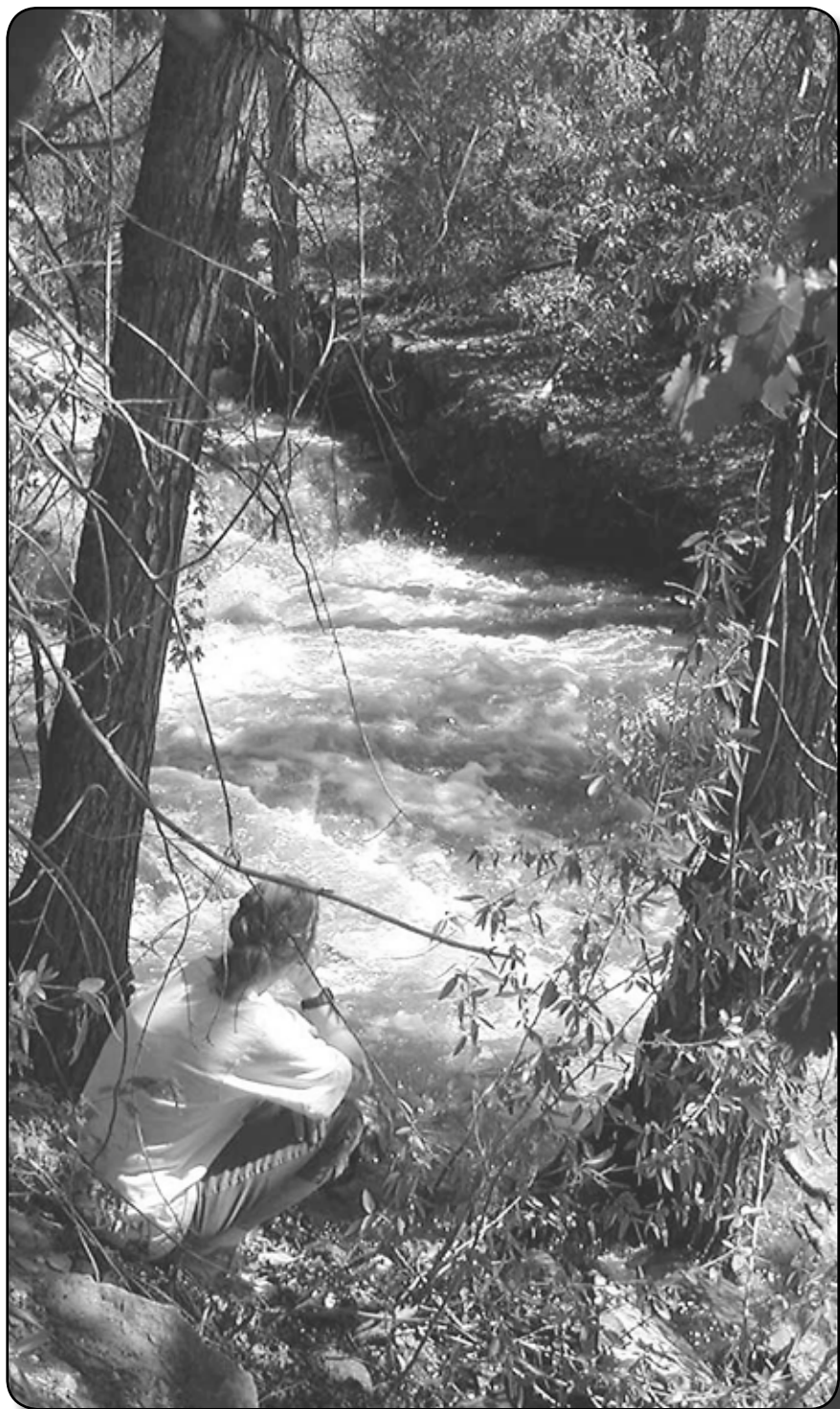
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“Hope is imagining and
fighting for what did not
seem possible before.”

—*Barack Obama, 2/16/08*
Eau Claire, Wisconsin



PROLOGUE

Why I am telling this story

When my wife, Kathy, was diagnosed with ALS in the spring of 2006, we were devastated. ALS, often called Lou Gehrig's disease, is a degenerative disorder that progressively destroys the nerves connecting your brain to your voluntary muscles. It is regularly described as being "rapidly progressive" and "invariably fatal," usually within a few years.

People with ALS often end up completely unable to move, trapped inside their own bodies while their minds stay fully functional. In the later stages of the disease, the person's only way to communicate may be with the blink of an eye or the twitch of a cheek muscle. While most cases of ALS begin in the legs and arms, Kathy's began in her throat and tongue, eliminating her ability to speak and swallow before it affected the other parts of her body.

The "experts" basically told us there was no hope. Instead of offering any suggestions to help Kathy get better, they advised us how to prepare for all of the awful things that lay ahead.

They showed us equipment that would help her breathe mechanically when she could no longer breathe on her own. They gave us literature about remodeling our home, so we'd be prepared when Kathy was strapped into a special wheel-

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chair or trapped in her bed. They told us about organizations that may be able to help with some of the many expenses that we would be facing as the disease progressed.

None of it was *if*. All of it was *when*.

For many years, a highlight of Kathy's summers had been getting out and riding her bicycle. During the summer of 2005, the year before she was officially diagnosed with ALS (but was already in its early stages), she'd biked more than 3,000 miles.

Even though her legs were still strong in June 2006, the ALS specialists advised Kathy against much physical activity. They told her that it would only increase the progression of the disease, and that once the nerves to her muscles were gone the muscles would atrophy and there was no way that any of that could be reversed. It was as if they not only wanted to tell her about the horrible things that lay ahead, but also take away the enjoyable things that she could still do.

By mid summer of 2006, Kathy could barely swallow and had to have a feeding tube surgically placed into her abdomen. The surgery itself went fine, but incompetent nursing care during her stay in the hospital nearly killed her. When she came home, a health care specialist was there to teach us how to use the feeding tube. To our amazement, the health care "expert" had such limited knowledge of the subject that we ended up having to teach ourselves how to use it with regular food that we prepared on our own.

Hopeless. No other word better describes our feelings about the situation we were in.

Throughout the summer of 2006, Kathy faithfully took her prescribed medications, even though it seemed pointless. One drug, the only medication that was FDA approved for the treatment of ALS, had the potential of slowing the disease's progression by a whopping 60-90 days. The side effects were that it could, and did, increase Kathy's symptoms of her ALS.

Hopeless.

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Another drug she was given was actually for an entirely different disease, but it was prescribed to her because of its side effect of causing severe dry mouth. The physician reasoned that it may help her with her drooling. It did. But combined with her other prescribed medications, it also essentially paralyzed her face, leaving her expressionless.

Hopeless.

Based on the information provided by the “experts,” Kathy and I started planning how to enlarge the bedroom window, so that when she was unable to get out of bed or move her head, she could still watch the birds at the feeder.

We worried about how to deal with our tiny bathrooms, which were much too small to accommodate the wheelchair and other assistive devices that we were told she would soon be needing.

Kathy wondered if she’d ever travel again; if she’d get to visit her daughter in Colorado.

Everything seemed so very hopeless.

Fortunately, Kathy was never any good at feeling sorry for herself. What she was especially good at was researching and solving problems.

One morning, she wrote on her white board, in large, bold letters: “I AM GOING TO BEAT THIS MONSTER WITHIN ME!”

Armed with a library card and access to the Internet, she started doing research. Most of what she found, primarily in medical reports and neurology journals, reinforced the hopelessness of her situation. Everyone had the same story; we have this great idea and if it works we’ll be testing it with mice in a few years and then, assuming we get the funding, we’ll move on to trials with humans and if that proves to be effective it may be available to the public in 10 or 15 years.

The life expectancy for a person with ALS is three to five years.

Kathy broadened her net and started looking in other

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places. Near the end of the summer of 2006, she came across information that changed our lives: she discovered that there were, in fact, people who believed and had demonstrated that the progression of ALS could be halted and even reversed. These folks, outside of the established medical system, believed that the pharmaceutically-trained physicians, with their emphasis on drugs, were not only on the wrong track but may even be doing more harm.

The turf-protecting medical experts, on the other hand, seemed to consider anyone who advocated for healing without drugs to be a quack.

But the medical establishment didn't have a solution, only press releases about possible cures that loomed somewhere in a future that Kathy was not expected to see.

She kept reading and learning. Most of the alternative health care professionals agreed on one essential point: The key to healing neuromuscular disease was to rid the body of environmental poisons that had accumulated over the years; poisons from such things as pesticides, contaminated food, pharmaceutical drugs and, especially, mercury from dental fillings. All of these products contained neurotoxins—poisons that damage or destroy nerve cells.

It made sense. ALS is all about damaged nerve cells. Get rid of the reason the cells are being impaired and you've got a shot at recovery.

Since the medical establishment had nothing to offer us, we decided it was a waste of our time, energy and emotions to continue seeing them. We politely told them to take a flying leap.

Kathy stopped taking the medications that had been prescribed. I started buying only organic and locally grown foods. Together, we went through our home and tossed out all of the potentially toxic cleaning, personal hygiene and health care products.

She felt better almost instantly. Within days of stopping the drugs that had nearly paralyzed her face, she regained her lovely smile.

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Hope.

Within a couple of weeks, we once again were going for long walks. By midwinter we were walking three and four miles at a time with no difficulty.

Kathy continued her research. One of the items strongly recommended was to have the amalgam fillings in her teeth removed. Amalgam fillings, often called silver fillings, are 52 percent mercury. Mercury is bad for you. We all know that. Mercury is banned from most products because it can do nasty things to your nervous system.

We asked our usual dentist to remove Kathy's fillings. He assured us that they were safe, no need to remove them.

Common sense seemed to indicate otherwise. Besides, even though Kathy had slowed the progression of her disease, she was still teetering on the brink of destruction. We'd rather err of the side of doing too much to help her than too little.

We began searching for a dentist who would remove the mercury fillings from Kathy's teeth. That was no easy task, especially since she couldn't swallow and the dental work would need to be done under general anesthesia.

During the next nine months, while we searched unsuccessfully for someone to safely remove the mercury from her mouth, she continued losing her strength, especially in her arms.

What she didn't lose was her determination to beat "this moldy old disease," as she'd begun calling it.

Eventually, in June 2007, we connected with the man who began the present-day campaign to ban mercury/amalgam fillings. He helped us arrange to get Kathy's fillings removed, and also worked very closely with us on monitoring and improving her blood chemistries. This was done through an even-more-restrictive diet, supplemented with minerals and vitamins. The goal was to remove the toxins that were in her system, while improving her body chemistry to the levels of someone who was in perfect health. In other words, give her body a chance to heal itself.

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It began to work.

By October of 2007, Kathy was able to swallow small amounts of water. She hadn't swallowed anything since August of 2006. A short time later she began to sense small movements and tingling in her tongue. She hadn't moved her tongue in about a year and a half.

She was also beginning to regain some of the strength in her arms. Not much, but even small improvements let us know that she was finally heading in the right direction.

To say that Kathy was thrilled would be an understatement. It had taken a lot of searching and a lot of work, but it was beginning to pay off.

Unfortunately, Kathy's story doesn't have a happy ending.

In late October of 2007 she lost her balance while getting something out of the refrigerator and fell backward, hitting her head and wrenching her shoulder. She hadn't been sleeping very well for a long time, but after the fall—because of the pain in her shoulder and her inability to get comfortable—she could barely sleep at all.

That went on for three weeks. As she grew more and more tired, she also became more and more restless, to the point where she couldn't even get in a short nap.

Three weeks after the fall, Kathy died of exhaustion. During the last few days of her life she managed to get, maybe, three or four hours of sleep total, including nighttime and naps. None of it was restful.

Her last night, she was in and out of bed at least 20 times. Since she had very little use of her arms and limited leg strength, getting in and out of bed took a tremendous amount of her energy. She had the will to go on, but not the strength.

So, so sad.

Kathy knew that she was heading in the right direction. Her body was beginning to show improvements that the "experts" said were impossible. She had begun lifting light

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weights again and doing low-impact exercises to strengthen her legs and arms. She was enthralled at the feeling of cold water once again going down her throat.

Kathy was only 57. I will miss her dearly.

I've organized this book around the last week of Kathy's life. Throughout, I've provided flashbacks to help you better understand the entire journey that we took in search of healing from her disease.

My wish is that her story will help you recognize the fact that there is hope for folks with neuromuscular disease. If one life can be saved because of the things that Kathy learned and experienced, then maybe her journey will not have been in vain.

—David Tank

Life should NOT be a journey to the grave with the intention of arriving safely in an attractive and well preserved body, but rather to skid in sideways, champagne in one hand, strawberries in the other, body thoroughly used up, totally worn out and screaming WOO HOO! WHAT A RIDE!



Kathy created this mini-poster in 2004, shortly before her illness began, and from then on had it displayed prominently at each of her desks.

Original source of the quote and photo unknown.



EPILOGUE

The River of Hope

One of the last big adventures that Kathy and I took was in the spring of 2006 when we went to search for the ivory-billed woodpecker in the swamps of Arkansas. It had recently been sighted there after being considered extinct for 40 years. Only one or two people had seen it, though, and its authenticity was questioned. Kathy was determined that we would be the next people to spot it.

After doing some research to know where to look, we hauled our canoe down to the Cache River Wildlife Area, found some locals who helped us get started, and spent a wonderful day maneuvering through terrain that was completely foreign to us. In fact it was foreign to most people, as very few souls had ever ventured into this nearly impassable bayou.

What we discovered was beyond our imagination. We were constantly searching for ways to navigate through the tangle of Cyprus roots and tupelo trees. The path was occasionally marked, thanks to someone who long before us had left a loose series of yellow spots painted on the sides of a few trees. Most of the time, though, we wove our way through and around the barriers completely on our own. Only once did we find solid land, so giving up wasn't an option. We had to see our way through to the end.

After eight hours of careful and skillful paddling, we

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came to the end of our quest. We hadn't seen the ivory-billed woodpecker. But we had discovered a whole slough of fascinating and exciting things we'd never seen before.

We had a few scary moments when we wondered if we'd ever find our way out, but each time we managed to move forward together.

After having experienced the elusive bird's habitat, we believed that it easily could have hidden there for 40 years without being detected.

Before we left the area, we bought matching tee-shirts with a picture of the ivory-billed woodpecker above the words "River of Hope."

A year later, on our return trip from Texas, we modified our route so that we could once again pass through the area where we had searched for the hard-to-find woodpecker. Being there again brought back many good memories.

Even though we hadn't found the mysterious bird, we had no regrets for making that earlier journey. We reminisced about it often, shared pictures with family and friends, and told the naysayers that, after having been there ourselves, we believed the elusive bird really did exist.

So it was on my journey with Kathy to discover the elusive secrets that could free her from the monster within her. Unfortunately, we reached the end of our journey before she was healed. But having been there ourselves, we believed that the prospect of healing really does exist.



Hope is Like a River

Hope is like a river;
it keeps you moving on.
Pulls you through the troubled waters,
helps you reach the calm.
Where it leads, you will follow,
rounding every bend.
The river moves you forward,
a river does not end.
There is always something new to find,
friends to meet,
sights to see.
Hope is like a river;
it keeps you moving on.
So don't give up,
keep moving on,
Turn the darkness
into dawn.
Hope is like a river;
it keeps you moving on.

—David Tank

