

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

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September 2020

Contents

Column	Author	Title
From The Editor's Desk	Donna McGary	We Will Survive 2020
The Scuttlebutt	Tom Whitworth	The New WebWhispers.org
VoicePoints	Dr. Brenda Villegas	The Power of Connection During COVID-19
Technially Speaking	Ron Matoon	WebWhispers' New Website
My Neck of The Woods	Don Renfro	My Key to Life
This Lary Life	WC Baker	Marilyn's Two-Part Birthday
The Agony & Ecstasy	Dr. Branton Holmberg	Chapter 12: "Takeaways"

From The Editor's Desk

Hello my friends,

I'm going to resist the temptation to just post a big sigh emoji and call it a day. I am sure I am not the only one who is thinking like the time-honored parental outburst..."I've had just about enough of your..." Choose your phrase LOL!! Challenging times indeed and now here in the US we have members of our WW community facing massive and unprecedented wildfires (hazy air from those fires on the west coast have shown up here in Maine due to Canadian wind streams!), dangerous flooding in the South and a toxic and divisive political climate everywhere on top of a world-wide pandemic that just won't quit. There are some days I just retreat to a good book altho the one I have latched onto isn't all that comforting or distracting. Historical novels, like *The Name of the Rose*, while hugely compelling, remind me that we humans are a nasty bunch oftentimes and if we can survive the Spanish Inquisition we can survive 2020 (and yes... this is a link to a Monty Python sketch)

<https://www.youtube.com/watch?v=Cj8n4MfhjUc>

I am not being flippant just trying to find some humor during this tempest. We have all survived a lot and what our writers express in this issue is that we have not just

survived but thrived. We have learned how to make the best of some pretty tough situations and we do it with grace and dignity and humor. There is some wonderfully inspiring and uplifting reading in this issue. From virtual support groups to finding your own happiness to celebrating life however you can we are a powerful voice for our community. Plus get a quick tour of our new website!

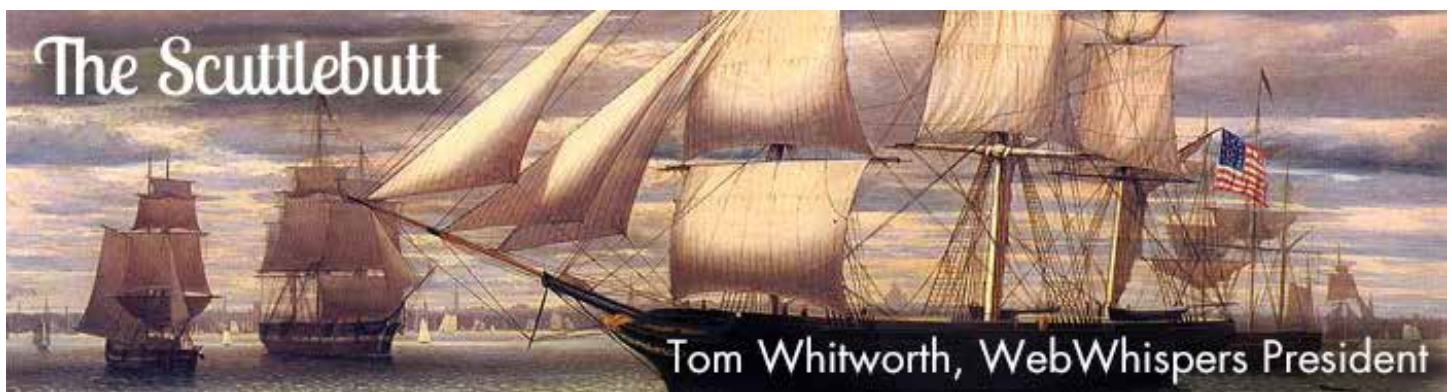
Stay safe, stay sane and stay in touch...safely!

Donna McGary

PS I found this quote and I love it

This day will never come again and anyone who fails to eat and drink and taste and smell it will never have it offered to him again in all eternity. The sun will never shine as it does today.... But you must play your part and sing a song, one of your best.

~ Hermann Hesse



The Debut of the New WebWhispers.org

Launching of our new website has made for an exciting week, for sure. The site will remain a constant work in progress and is actually being worked on today, I am sure. You may or may not notice a wrinkle or two but be assured, they are being ironed out. We have a plan in place to keep the website both relevant and current. If

you haven't seen much of it yet, I invite you to stroll through the website rather than just scroll through it. I'm confident you will enjoy the improvements, especially if you are accessing us on a mobile device. We are proud of the website, and of our Webmaster Ron Mattoon!

Ron has devoted immeasurable time and effort toward this project for a very long time. Without his devotion to WebWhispers, the project may have been simply beyond our grasp. Almost anything that could go wrong, did. For instance, having to start over after the first year's work after we learned that the software in use would no longer be supported. With his innate ability and a lot of learning under his belt, Ron had to go back to square one. As if that were not enough challenge, there is the living of life and dealing with personal tragedy while seeing this project to fruition. Leaders, members, and friends of WebWhispers, along with website users worldwide owe Ron a debt of gratitude. Thank you Ron Mattoon!

The previous website was developed in 2006 and underwent very little in the way of improvement, though it grew exponentially with the constant adding of information for our users. To avoid having the current site become outdated as the old one did, we authorized an annual website maintenance fund beginning in 2018 of \$1,000 to \$2,000 per year. The higher number appears to be a safer bet. Half of that amount is now covered by a single annual contribution from one of our supporters. Liz Anne Casey Potamianos has contributed \$1,000 annually in memory of her father, Joseph L. Casey, past president of WebWhispers, Inc. After speaking with Liz in 2018, this generous gift is earmarked for our Website Maintenance Fund, which is now at \$3,000.

The website was expensive at around \$15,000 and we knew that going in. Before the project could begin, some support from outside WebWhispers was needed to avoid a huge hit on our finances. While pondering this, I heard from one of our members, Rita Burfitt, that a caregiver she knew in New Jersey, Christine Troianello, had lost her husband Jerry to cancer. Jerry was an active member of North Star Athletic Club who wanted to contribute to a laryngectomy-related charity in his memory. Rita, of course, had suggested WebWhispers. I was happy to express interest in what was thought to be \$1,500 and explained to Mrs. Troianello, that if WW were selected, the money would be used toward redevelopment of our website. The club hosted a golf tournament in memory of Jerry Troianello and Christine had selected WebWhispers as the recipient of the proceeds. Yes, I teared up opening that envelope, surprised that the enclosed check was for \$2,500! Jerry and Christine Troianello and the North Star Club will always be a part of us. The contribution paved the way for approaching others and being able to say we had something to work with. I thought of our vendors, many

of whom had often asked me to let them know what they could do for WebWhispers. Constantine Delvantes then of InHealth Technologies, was thrilled to help kick off the project with a donation of another \$2,500. Doug Sanchez of Atos Medical came through with a donation of \$3,000. Richard Najarian of Bruce Medical kicked in \$500, even though Bruce is among our top contributors already. Though they prefer anonymity, the annual contribution of Tom & Dorothy Lennox of Luminaud, Inc. was in the mix since 2018 to the tune of \$1,500. Still others support WebWhispers financially, with our annual dinner, and keeping our loan closet alive (Jim Lauder, Lauder Enterprises) and including our brochure in the worldwide shipments to customers (Tom Dodson of Romet). I apologize if I have inadvertently failed to mention someone here. It would be due to my chronic case of CRS and I certainly mean no harm.

I'm sure I speak for the WebWhispers Board of Directors, our members, and our website visitors all over the world in expressing our sincere gratitude to Ron Mattoon for his dedication, Liz Anne Casey Potamianos, Christine Troianello and the North Star club for their thoughtfulness and generosity, and to each of the vendors of products we use for their continued and unwavering support of WebWhispers, Inc.

Now, if for some reason you are not a member of WebWhispers, here is how to take care of that today: <https://webwhispers.org/join-us/>

*Enjoy, laugh, and learn,
Tom Whitworth
WebWhispers President*



Laryngectomy to Laryngectomy, Caregiver to Caregiver: The Power of Connection During COVID-19

As we enter our sixth month into the pandemic in the United States, we have learned about managing and living a “new normal.” Transitioning to virtual conferences seemed to be a natural occurrence when we were mandated to shelter-at-home. How does one continue social interaction and reduce the chances of isolation? The virtual support meetings gave us an opportunity to address this.

Our virtual support meetings started out with a major focus on the pandemic. The group members discussed how they were getting groceries (e.g., who delivered groceries in a timely manner), keeping their homes sanitized, managing their households with children at home and working from home. Many meetings discussed precautions, PPE (use of face mask and cover or mask over stoma for a laryngectomy), current fears and concerns. But now, five months later, the meetings have turned into an environment of increased social interaction – lots of laughter and support.

At our last meeting, a new patient and her family member joined the group. Discussion started out about ways to reduce anxiety which resulted in a rich discussion of fun hobbies and activities and thoughtful reflection from the patients with regard to transitioning back to “normal” activities. The group has provided a weekly platform not only to consistently exchange information but to share life experiences. Members shared their favorite things from humidifiers and walking to get exercise to eating slippery foods like mangoes.

The group, which celebrated its 10-year anniversary this year, has always been about sharing and caring for each other since the very first meeting. Members have been active in community outreach by reaching out to patients who are preparing for surgery, just had surgery, or sharing supplies for fellow members in need of HMEs due to a delay with receiving supplies. Earlier in the pandemic, the Provox Micron HME was recommended as a good product to use when out in the community. When a few members were unable to obtain this item, support group president Marilou Percival mailed out boxes to those in need.

The atmosphere is casual even when discussion include serious topics such as dealing with cancer concerns and

fear of getting COVID if they go out in the community. The group members remain strong in their resolve and empathetic while listening to their peers discuss topics that may be sometimes painfully familiar. Virtual conferences have also provided an easy way to invite speakers from the healthcare team. To encourage improving physical activity during home isolation, our USC physical therapist Dr. Kimi Yamada offered the group exercise tips and ways to stay active when most of us remained at home. Dietitians have also participated by encouraging healthier eating during this time. Dr. Niels Kokot, our head and neck surgeon at USC Caruso Department of Otolaryngology-Head and Neck Surgery, has provided COVID-19 updates and helped ease some of the fears.

These virtual conferences have provided inspiration to members by being given the chance to connect with other laryngectomees across the country to learn more about their journeys. Dr. Itzhak Brook visited the group early on during the pandemic and answered questions and provided suggestions for laryngectomees on how to keep safe and healthy during this time. Another special guest, David Hayles, shared his stories and memorable photos during his intercontinental experiences on his electric-assisted bicycle which motivated all of us to find our next adventure.

The group focus has always been on providing information and most of all support. During this pandemic, it has proven to be so much more for everyone. The sharing in the group—full of laughter, smiles and sometimes tears—a unique bond has been created for those who have traveled similar paths. The group enthusiastically welcomes new members into the group and as one patient has said, “I came in as a stranger and left with a new group of friends.”

NuVoices Los Angeles Laryngectomy and Caregiver Support Group meets Monday evenings at 6 pm PST.

Visit <https://www.nuvoicesla.org/> for more information or email Dr. Brenda Villegas at Brenda.Villegas@med.usc.edu.

Dr. Brenda Villegas is a speech-language pathologist and assistant professor of clinical otolaryngology in the USC Caruso Department of Otolaryngology-Head and Neck Surgery in Los Angeles, California.

You can contact Dr. Villegas at Brenda.Villegas@med.usc.edu.



WebWhispers New Website: <https://webwhispers.org>

We attempted to keep the new site fresh and less cluttered than the old site. We wanted a welcoming appearance while making it easier to find information. To do this zones of information were created. At the top of the page are basically the business sections. This includes the Members' Area, a Join Us form and Donation information. Below that is the About Us section with contains the awards section, administration, sustaining members, memorial of lost members, information on our founders and the meet us page with pictures and information on the people that make WebWhispers work.

There are also activities, services and resources options to easily access. The resources section is the main part of the library with sections for laryngectomies, caregivers, and professional members. Some pages are available in more than one section as there would be interest about that information between all members.

The picture banner at the top scrolls through the pictures to give the site a fresh look. The picture of the iceberg was selected because what most people see is only on the surface. We all have so much more to our lives that is under the surface; not visible to others.

Many of the pages contain an outline of information on the left side to help you find information in that section. If you click on anything in that outline it will take you to that section so you do not have to scroll down to it.

Just below the pictures are four sections that include the activities including our IAL awards dinner information, cruise information, email guidelines and Facebook guidelines. The services section includes information on local clubs, scholarship information for the IAL Voice Institute, and our loan closet. The suppliers' section has listed all the people that help laryngectomees live our lives. The general information contains access to insurance information, computer tips, reading materials and information on volunteering.

Below the four categories is a Coming Events section. The most current event will be automatically posted in the box and if you click on it you will go to that information. The view all events box will take you to a list of all the events listed.

Next to that the latest Whispers on the Web Newsletter is posted. Click on the box and you will go to that newsletter. The view past newsletters box below will take you to a listing of past newsletters and you can access them there.

The next box below that is direct access to safety concerns as a Laryngectomee. This includes 911 and CPR issues, car concerns, anesthesiology concerns and identification options.

Below the safety section is the main library resources sections. As mentioned before it is divided into 3 sections for laryngectomees, caregivers and medical professionals. The subsection in these areas are divided into areas as in pre-surgery, in the hospital and post-surgery as well other subsections. We tried to keep the page names the same as the original site to help those that have used our library in the past find information. There is also the outline listing on the left of the page and a search box to help you find information. The image used on the Laryngectomee section has special meaning. The picture is of a

small boy reaching for a book in the library, while being lifted up by a giraffe. It represents our library and the boy's need to learn. The giraffe is important because it is the only animal born without vocal cords. This image was found by Jack Henslee.

My attempt was to make the site have a friendly, welcoming feeling and not just be a source for information but one of support and camaraderie.

At the top and bottom of the page is a link to Facebook and Twitter. If you are a member of the WebWhispers Facebook page it will take you directly to our page.

I hope you find the new site easy to use and very helpful. As always a website is a work in progress and updating and correction are always in process.

Best wishes and enjoy the site,

Ron Mattoon
WebWhispers Webmaster
Seattle 2010



My Key to Life

By Don Renfro

When I was 5 years old, my mother always told me that happiness was the key to life. When I went to school, they asked me what I wanted to be when I grew up. I wrote down "happy". They told me I didn't understand the assignment, and I told them they didn't understand life.

~ John Lennon

I love this quote. It summarizes so much of life for me. I remember growing up and answering the age old question "what do you want to be when you grow up?" Since about the third grade, the answer to that question for me was an architect. I truly believed at that young age that it was the career that would complete my puzzle for happiness.

My parents were less than tolerant of anything short of good grades. I got from that that their belief was that happiness correlated with good grades. One could not end up happy without having received good grades while they were in school.

For me, getting good grades was not the concern that it was for my older sister. I was more concerned with being happy at the time than any happiness I might have in my future as a result of good grades at that time. I was far more concerned with having fun then and being popular and playing sports.

In hindsight I believe I lived my life growing up as I guess most children do, living in the moment in search of immediate gratification.

As I got older and left high school I believed that happiness was always around the corner. After I get my degree I will be happy. After I get a new car I will be happy. After I live in a nice neighborhood then I will be happy. Happiness was always the result of something.

It wasn't until my late 30's or early 40's I learned that for me happiness was not the result of something but the goal to achieve in life. The reality was that I always had everything I needed to be happy, as well as have everything I need now to be happy. When happiness becomes a state of mind it is always obtainable.

I remember hearing the phrase "do you want to be right or do you want to be happy?" when I was younger. In my youth

life was a competition and to win the competition meant to be happy. That could not have been further from the truth! Today I don't have to compete I just have to be happy. I say that as if it is such a simple task. The truth is that at different times it can be a real challenge to just be happy. Being human, happiness is a very natural and experienced emotion. The fact is that so is hurt, sadness, fear, disgust as well as many others. With such a wide variety of emotions the fact is that many emotions are in direct conflict with feeling happy.

The truth is for me that even when the key to life is to be happy that will not always be the case. Sometimes it is ok to just feel bad. Feeling bad does not equate to losing sight of my key to life, happiness.

I know it is important to know what won't make me happy but it is equally important knowing what I am happy doing.

When I was growing up Christmas and birthdays were a big deal in my house. For one reason my mother's birthday was December 23. She grew up without her birthday being acknowledged because it was too close to Christmas. Because of that you did not forget my mother's birthday and live to tell about it. So for me it brought me much joy and happiness to find a Christmas gift or birthday gift that was special to the person receiving it. To this day I am very happy to find the gift that leaves the recipient in wow. That is one way I live my key to life.

Another way I can find my key to life is doing the right thing just because it is the right thing to do. When I was younger I got off work and went to the bank to cash my check. When I cashed it at the drive up window the teller gave me an extra \$100 bill. I ended up giving it back. Not at the drive up but after going home. I have to remember about myself that I will always be happier when I can look back on my actions and know I did the right thing. That is not always easy to remember and many times takes effort on my part to look beyond the immediate gratification to see the long term happiness I gain.

Today I work hard to remember all I want is to be happy and remembering that helps me to keep the rest of life in perspective.



This Lary Life

Marilyn's Two-Part Birthday

W. C. Baker

I propose a word for the seemingly gender-specific malady of forgetting birthdays and anniversaries, or, if remembered, being unable to celebrate them with the attention they deserve. Maleady? I don't know if it exists in all cultures, but I know I'm not the only American male who stumbles through such situations with the awkwardness of a little boy buying a tiny bottle of Evening in Paris for his mother at Christmas. She always expressed surprise and delight as she added the new gift to the slowly growing accumulation on her dressing table. I never outgrew this awkwardness, nor the feelings of inadequacy. I almost always remember the dates, but I never quite know what to do to meet the expectations of the honoree. Over recent years, I feel that my efforts, though sincere, have left something to be desired. I was determined that this year I would make up for all those previous short comings. Toward this end, I started my procrastinations much earlier and was actually able to get a suitable gift a whole week before Marilyn's birthday. I wasn't able to get a card until the day before, but that was good enough.

I had asked Marilyn to think about what she wanted to do for her birthday, but there are not too many options in this time of COVID oppression. She had taken me to see Hamilton for my birthday back in January. Well, there was simply no way to match that under the circumstances. Watching Vera on PBS wouldn't even come close. Marilyn decided she wanted to do a walk at Pt. Reyes, maybe to the lighthouse if it was open. It wasn't, so we went to Drake's beach instead. This is not as wimpy as it may sound.

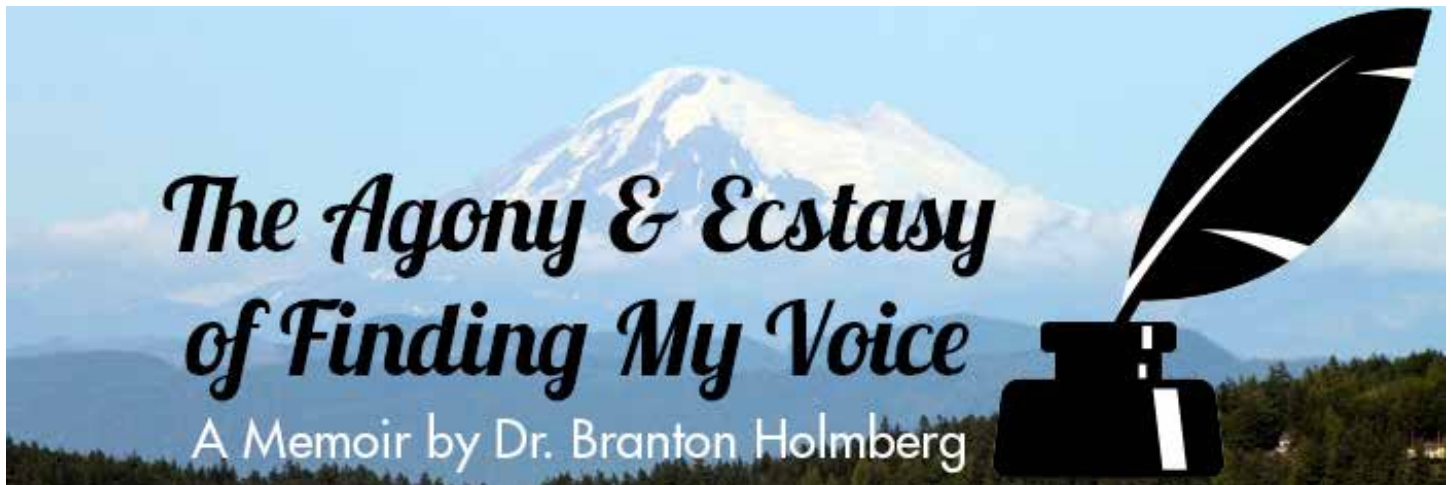
Marilyn was diagnosed with Parkinson's Disease 23 years ago at age 50. She has done remarkably well for all these years, and has earned respect and admiration of all who know her. But lately she has been having some problems, falling a lot and having trouble moving her feet and keeping her balance. Before she used to take her walking poles and end up striding, carrying them in her hands. Lately she has started with the poles and, when she had to, would switch to the walker that I always bring along for when she would need the extra support. She would then use the walker until her legs gave out. Then she would sit on the walker and let me push her back to the car, usually just the last 100 yards or so after walking about a mile with poles and walker. In spite of the fact that we could not use the walker in the sand, she took her poles down to the beach and chased the gulls as best she could, trying to make them fly, maybe this one last time. Unfortunately, she only managed to work up enough speed to make them run out of her way. After this frolic, we headed back up the beach to the car, with my firm grip on the back of her coat to keep her from falling. At the car, I noticed a face mask under the front bumper that looked like hers. I let go of her to retrieve the mask, took a

step away and she fell face first onto the pavement, abrading her left knee and her cheek.

My apartment in San Rafael was closer than hers in Terra Linda, so we stopped there so she could clean her wounds. By the time she was finished, it was too late to go down to Fourth Street, which they close to traffic on Thursday nights. I fixed a salad and some leftover chicken piccata and we watched the last bit of Vera on PBS after all. Ah well, she appreciated the gift and the sincerity of my other efforts, but I knew that she had to have been disappointed, as was I.

Life usually gives us opportunities to make good on our intentions and Sunday provided an opportunity to do something to make the birthday situation better. However, opportunities don't always work out the way you might have hoped or expected. I suggested a walk around the top of Mt. Tam (Tamalpais). She would walk with her poles until she needed the walker that I would bring along. It is a fantastic walk, starting with views of the Pacific to the west and continuing with Mill Valley the Golden Gate Bridge and San Francisco to the south. Continuing around, you can see Alcatraz, and the Bay bridge going into Oakland and Berkeley. Coming around more we find San Quentin Penitentiary where the COVID has run rampant. In spite of the COVID it is a breathtaking view and ought to allow some atonement for my failure on Marilyn's birthday.

It had been as much as a year since we had taken the Fairfax/Bolinas Rd up to the ridge to Mt. Tam. It climbs through rounded hills, now golden after 5 months without rain, the road continues over the dam that contains Alpine Lake. Winding up the narrow road through the redwoods, being surprised by the sudden appearance of a car coming downhill around the curve, Marilyn asked if I liked driving there. "I love it", I said, "not the driving but the drive. It's beautiful." And it was. All was going well until we got to the ridge and found the gate closed, preventing our access to Mt Tam. Nothing to do, but turn back to Fairfax, or go on to Bolinas. Still hoping to rescue the situation, we checked out Bolinas for a place to eat by the ocean. No luck, so we headed north on Rt. One to Olema, in the San Andreas Fault and at the edge of Pt Reyes National Seashore. The tables, umbrellas and heaters were set up in a parking lot. We were seated at a table appropriately distanced from a table of four men, and four women in their 40s or 50s. They were thinking up and singing "happy" songs. When I turned to join them, thumb to stoma, for a rendition of Happy Talk, they asked me what my favorite happy song was. The only thing I could think of was Ode to Joy which didn't really fit the frivolity of the situation. After our dinner, Marilyn asked for an Ice Cream Sandwich with a candle in it. When it was served, the table of happy song singers stood and sang Happy Birthday. Marilyn Beamed. I got goose bumps. The Birthday was saved.



Chapter 12 “Takeaways”

Wish not to be someone you are not, make the most of who you are.

During my childhood years, up to the time I came face to face with dealing with my poor self-image of being a harelip who talked through his nose, there was a desire to be someone without that disfigurement and speech impediment. It was only when Dr. Crawford forced me to deal with how I was seeing myself, through the ruse of taking me to court for breach of contract that I took the action that completely transformed my life.

That action was revolutionary and led me into professional arenas in my life I never dreamed possible. When I realized I'd created a distorted, and limiting, self-image of my ability to communicate clearly, it opened my mind to exploring other dimensions of myself I'd similarly distorted.

I'd always put myself in the background to try to be as inconspicuous as possible. When I found the face and the voice I'd been looking for my whole life, I no longer wanted to be inconspicuous but the transition took time to develop and required me to take risks I'd never thought of taking before.

Getting in front of my classes and lecturing transitioned into getting in front of groups and making professional presentations to them as an expert in human dynamics in businesses and organizations. The challenges were significant with the multitude of clients I worked with as a consultant over a span of 36 years.

Those challenges led me to take risks in developing

numerous human interaction techniques in organizations that would take my clients where they wished to go. It was my new found willingness to take risks that allowed me to follow a career path that led me to ever greater rewards. I went from being a nearly overwhelmed graduate teaching assistant, to working with clients in different types of organizations that constantly challenged me to go beyond where I'd been before, and where they'd been before.

Did I fail from time to time? Sure. Did I get up and keep going? Absolutely. Those challenges were more exciting and dynamic than I'd ever dreamed possible.

This came about when I realized I was the master of my destiny. I believe our self-awareness controls every element of who we are and what we believe about ourselves. I know mine certainly does. It's taken me a lifetime to learn the many ramifications of that insight but I feel I've learned a great deal, and it has now opened the doors of creative writing to me.

I've come to realize the world I know is solely my world and only I know what that world really is. That's true for every living entity because no two animate things live exactly the same way. Every life is a life unique to the individual entity living it. No two people can occupy the same space and it's that space around us, and what we do with it that makes us the person we are.

We exist in an amazingly complex world. It is from that world we become who we are from the moment we're conceived. Each of us learns differently. That has to be. We're unique not only in our biological makeup but in the way we learn from what's going on around us. No two people see, hear, taste, feel, smell and use their minds to understand their sensations in the same way. It's not possible.

If I were to compare myself to a computer I can see many parallels. My DNA is what established the programming patterns that created who I would become physically and how I'd learn to understand my world. They were laid down the moment I was conceived. Half of that programming came from my father and half from my mother. Those two factors alone make me completely unique.

My genetic patterns expanded in a programmed way during my development in the womb and have continued to shape me throughout my life. There's never been a creation like me, and will never be again. I'm the result of an infinite pattern of possibilities, and the only pattern of those possibilities that's ever existed.

My brother was a similar genetic pattern because he too came from the DNA of our parents but we're totally different human beings. This was due not only to our genetic differences, even though we have the same parents, it's in large part due to the individual worlds we lived in and learned from. He had more than 3 years of life programming before I was even born, and none of his programming was the result of a physical disfigurement and speech impediment.

My life then has been the result of how I've lived every moment and how my genetics, and my conscious awareness of each thing I've learned from the world around me, became my interpretation of life and made me who I am.

This is, I think, is the pattern of all life and results in the life of every living thing being absolutely unique. I cherish that insight and know now my life was meant to be exactly as it has turned out with all the agonies and ecstasies that have made it what it is.

When I leave my mortal existence, my world as I've lived it will disappear. The only traces of it will be in the memories of those who knew me, and from whatever those wanting to know about me can find in records, or other tangible things I've left behind such as my writings.

Will technology one day take us to the point we can enter the life experiences of other living entities and understand them as they exist in their world? Could that be possible? I doubt it because we'd still be seeing their world in the context of the only world we know which is our own.

This is what led me to write this memoir. I want to leave a tiny remembrance of my existence for others,

especially my descendants, to get a glimpse of my life as I lived it. What a wonder it would be if we all did that.

I know now the only reality I've ever known is what is created in my consciousness as a result of how I live in the world around me. What I find exciting as each day passes is to learn how others see, hear, feel, taste, smell and think about the world as they know it and describe it to me. I'm able to do this through all the images my mind gathers from them in whatever form they share their world through things like books, television, movies, radio, the classroom, the workplace, travel, social interactions and whatever other forms of knowledge and understanding my awareness opens up to me.

To all who've touched my life, no matter how you've touched it, I'm forever indebted because you've helped make me who I am and I appreciate that more than I'm able to express.



WebWhispers is an Internet based support group. Please check our home page for information about the WebWhispers group, our email lists, membership, or officers. For newsletter questions, comments or contributions, please write to editor@webwhispers.org

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