MY STROKE OF INSIGHT

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INTRODUCTION
Heart to Heart, Brain to Brain

Every brain has a story and this is mine. Ten years ago, I was at Harvard Medical School performing research and teaching young professionals about the human brain. But on December 10, 1996, I was given a lesson of my own. That morning, I experienced a rare form of stroke in the left hemisphere of my brain. A major hemorrhage, due to an undiagnosed congenital malformation of the blood vessels in my head, erupted unexpectedly. Within four brief hours, through the eyes of a curious brain anatomist (neuroanatomist), I watched my mind completely deteriorate in its ability to process information. By the end of that morning, I could not walk, talk, read, write, or recall any of my life. Curled up into a little fetal ball, I felt my spirit surrender to my death, and it certainly never dawned on me that I would ever be capable of sharing my story with anyone.

My Stroke Of Insight: A Brain Scientist's Personal Journey is a chronological documentation of the journey I took into the formless abyss of a silent mind, where the essence of my being became enfolded in a deep inner peace. This book is a weaving of my academic training with personal experience and insight. As far as I am aware, this is the first documented account of a neuroanatomist who has completely recovered from a severe brain hemorrhage. I am thrilled that these words will finally go out into the world where they might do the most good.

More than anything, I am grateful to be alive and celebrative of the time I have here. Initially, I was motivated to endure the agony of recovery thanks to the many beautiful people who reached out with unconditional love. Over the years, I have remained obedient to this project because of the young woman who contacted me out of desperation to understand why her mother, who died from stroke, had not dialed 9-1-1. And because of the elderly gentleman, who was laden with worry that his wife had suffered enormously while in a coma before her death. I have remained tethered to my computer (with my faithful dog Nia on my lap) for the many caregivers who have called in search of direction and hope. I have persisted with this work for the 700,000 people in our society (and their families) who will experience stroke this year. If just one person reads "The Morning of the Stroke," recognizes the symptoms of stroke and calls for help - sooner rather than later, then my efforts over the last decade will be more than rewarded.

My Stroke of Insight falls into four natural divisions. The first portion, "Jill's Pre-Stroke Life," introduces you to who I was before my brain went offline. I describe why I grew up to be a brain scientist, a little of my academic journey, my advocacy interests, and my personal quest. I was living large. I was a brain scientist at Harvard, serving on the national board of NAMI (the National Alliance on Mental Illness) and traveling the country as the *Singin' Scientist*. I follow this very brief personal synopsis with a little simple science, which is designed to help you understand what was going on in my brain biologically on the morning of the stroke.

If you ever wondered what it might feel like to have a stroke, then "The Morning of the Stroke" chapters are for you. Here, I take you on a very unusual journey into the step-by-step deterioration of my cognitive abilities, as viewed through the eyes of a scientist. As the hemorrhage in my brain grew larger and larger, I relate the cognitive deficits I was experiencing to the underlying biology. As a neuroanatomist, I must say that I learned as much about my brain and how it functions during that stroke, as I had in all my years of academia. By the end of that morning, my consciousness shifted into a perception that I was at *one* with the universe. Since that time, I have come to understand how it is that we are capable of having a "mystical" or "metaphysical" experience - relative to our brain anatomy.

If you know of someone who has had a stroke or some other type of brain trauma, then the recovery chapters may prove to be an invaluable resource. Here, I share the chronological journey of my recovery, including over fifty tips about things I needed (or didn't need) in order to recover completely. My "Recommendations for Recovery" are listed in the back of the book for your convenience. I hope you will share this information with anyone who may benefit.

Finally, "My Stroke of Insight" defines what this stroke has taught me about my brain. At this point, you will realize that this book is not really about stroke. More accurately, the stroke was the traumatic event through which the insight came. This book is about the beauty and resiliency of our human brain because of its innate ability to constantly adapt to change and recover function. Ultimately, it's about my brain's journey into my right hemisphere's consciousness, where I became enveloped in a deep inner peace. I have resurrected the consciousness of my left hemisphere in order to help others achieve that same inner peace - without having to experience stroke! I hope you enjoy the journey.

ONE

Jill's Pre-Stroke Life

I am a trained and published neuroanatomist. I grew up in Terre Haute, Indiana. One of my older brothers, who is only 18 months older than I, was diagnosed with the brain disorder schizophrenia. He was officially diagnosed at the age of 31, but showed obvious signs of psychosis for many years prior to that. During our childhood, he was very different from me in the way he experienced reality and chose to behave. As a result, I became fascinated with the human brain at an early age. I wondered how it could be possible that my brother and I could share the same experience but walk away from the situation with completely different interpretations about what had just happened. This difference in perception, information processing, and output motivated me to become a brain scientist.

My undergraduate academic journey began at Indiana University in Bloomington, Indiana in the late 1970s. Because of my interactions with my brother, I was hungry to understand what "normal" was at a neurological level. At that time, the subject of neuroscience was such a young field that it was not yet offered on the IU campus as a formal area of specialization. By studying both physiological psychology and human biology, I learned as much as I could about the human brain.

My first real job in the world of medical science turned out to be an enormous blessing in my life. I was hired as a lab technician at the Terre Haute Center for Medical Education (THCME), which is a branch of the Indiana University School of Medicine hosted on the campus of Indiana State University (ISU). My time was evenly divided between the medical human gross anatomy lab and the neuroanatomy research lab. For two years, I was immersed in medical education and, while mentored by Dr. Robert C. Murphy, I fell in love with dissecting the human body.

Bypassing the master's degree, I spent the next six years officially enrolled in the ISU Department of Life Science Ph.D. program. My course load was dominated by the first-year medical school curriculum, and my research specialty was neuroanatomy under the guidance of Dr. William J. Anderson. In 1991, I received my doctorate and felt competent to teach Human Gross Anatomy, Human Neuroanatomy, and Histology at the medical school level.

In 1988, during my time at the THCME and ISU, my brother was officially diagnosed with schizophrenia. Biologically, he is the closest thing to me that exists in the universe. I wanted to understand why I could take my dreams and connect them to reality and make my dreams come true. What was different about my brother's brain such that he could not connect his dreams to a common reality and they instead became delusions? I was eager to pursue research in schizophrenia.

Following commencement from ISU, I was offered a postdoctoral research position at Harvard Medical School in the Department of Neuroscience. I spent two years working with Dr. Roger Tootell on the localization of Area MT, which is located in the part of the brain's visual cortex that tracks movement. I was interested in this project because a high percentage of individuals diagnosed with schizophrenia exhibit abnormal eye behavior when watching moving objects. After helping Roger anatomically identify Area MT's location in the human brain,[1] I followed my heart and transferred into the Harvard Medical School Department of Psychiatry. It was my goal to work in the lab of Dr. Francine M. Benes at McLean Hospital. Dr. Benes is a world-renowned expert in the postmortem investigation of the human brain as it relates to schizophrenia. I believed this would be how I could make my contribution to helping people stricken with the same brain disorder as my brother.

The week before I began my new position at McLean Hospital, my dad Hal and I flew to Miami to attend the 1993 annual conference of NAMI, the National Alliance on Mental Illness.[2] Hal, a retired Episcopalian minister with a Ph.D. in counseling psychology, had always been an advocate for social justice. We were both motivated to attend this convention to learn more about NAMI and what we could do to merge our energy with theirs. NAMI is the largest grassroots organization dedicated to improving the lives of persons living with serious mental illness. At that time, NAMI had a membership of approximately 40,000 families with a loved one who is psychiatrically-diagnosed. Now NAMI has a membership of approximately 220,000 families. The National NAMI organization advocates at the national level while the State NAMIs advocate at the state level. In addition, there are over 1100 local NAMI affiliates scattered around the country providing support, education, and advocacy opportunities for families at the community level.

That trip to Miami changed my life. A group of around 1,500 people, comprised of parents, siblings, offspring, and individuals diagnosed with severe mental illness, gathered together for support, education, advocacy, and research-related issues. Until I met other siblings of individuals with mental illness, I had not realized what a profound impact my brother's illness had had on my life. In the course of those few days, I found a family of people who understood the anguish I felt at the loss of my brother to his schizophrenia. They understood my family's struggle to help him access quality treatment. They fought together as an organized voice against the social injustice and stigma related to mental illness. They were armed with educational programs for themselves, as well as for the public, about the biological nature of these disorders. Equally important, they rallied with the brain researchers to help find a cure. I felt that I was in the right place at the right time. I was a sibling, a scientist and passionate about helping people like my brother. In my soul I felt that I had found not only a cause worthy of my effort, but also an extended family.

The week after the Miami convention, I arrived at McLean Hospital stoked and eager to start my new job in the Laboratory for Structural Neuroscience, the research domain of Dr. Francine Benes. I was all a-buzz and thrilled to begin my postmortem investigations into the biological basis of schizophrenia. Francine, whom I affectionately call the "Queen of Schizophrenia," is an amazing research scientist. Just watching how she thinks, how she explores and how she pieces together what she learns from data was a total joy for me. It was a privilege to witness her creativity in experimental design and her persistence, precision, and efficiency in running a research lab. This job was a dream come true. Studying the brains of individuals diagnosed with schizophrenia brought me a feeling of purpose.

On the first day of my new job, however, Francine threw me for a loop when she informed me that the infrequency of brain donations from families of individuals with mental illness had created a long-term shortage of brain tissue for postmortem investigation. I couldn't believe what I was hearing. I had just spent the better half of a week at National NAMI with hundreds of other families with members diagnosed with severe mental illness. Dr. Lew Judd, a former director of the National Institute of Mental Health, had moderated the research plenary, and several leading scientists had presented their research. NAMI families love sharing and learning about brain research, so I found it mind-boggling that there could be a lack of donated tissue. I decided this was merely a public awareness issue. I believed that once NAMI families knew that there was a research tissue shortage, they would promote brain donation within the organization and resolve the problem.

The next year (1994), I was elected to the National NAMI Board of Directors. It was a thrill for me to be of service to this wonderful organization, a huge honor and responsibility. Of course, the base of my platform was the value of brain donation and the shortage of psychiatrically-diagnosed tissue available for scientists to do their work. I called it the "Tissue Issue." At the time, the average age of a NAMI member was 67 years old. I was only 35. I felt proud to be the youngest person ever elected to this board. I had lots of energy and was raring to go.

With my new status within the National NAMI organization, I immediately began keynoting at State NAMI annual conventions all around the country. Before I began this venture, the Harvard Brain Tissue Resource Center (Brain Bank[3]), which was positioned right next to the Benes Lab, was receiving fewer than three brains a year from psychiatrically-diagnosed individuals. This was barely enough tissue for Francine's lab to do its work, much less for the Brain Bank to supply tissue to the other reputable labs that requested it. Within a few months of my traveling around and educating our NAMI families about the "Tissue Issue," the number of brain donations began to increase. Currently, the number of donations from the psychiatrically-diagnosed population ranges from 25-35 per year. The scientific community would make good use of 100 per year.

I realized that early on in my “Tissue Issue” presentations, the subject of brain donation would make some of my audience members squirm uncomfortably. There was this predictable moment when my audience would realize, “Oh my gosh, she wants MY brain!” And I would say to them, “Well yes, yes I do, but don’t worry, I’m in no hurry!” To combat their obvious apprehension, I wrote the Brain Bank jingle titled “1-800-BrainBank!”[4] and began traveling with my guitar as the *Singin’ Scientist*.[5] As I neared the subject of brain donation and the tension in the room began to rise, I’d pull out my guitar and sing for them. The Brain Bank jingle seems to be just goofy enough to effectively dampen the tension, open hearts, and make it okay for me to communicate my message.

My efforts with NAMI brought deep meaning to my life and my work in the lab flourished. My primary research project in the Benes lab involved working with Francine to create a protocol where we could visualize three neurotransmitter systems in the same piece of tissue. Neurotransmitters are the chemicals with which brain cells communicate. This was important work since the newer atypical antipsychotic medications are designed to influence multiple neurotransmitter systems rather than just one. Our ability to visualize three different systems in the same piece of tissue increased our ability to understand the delicate interplay between these systems. It was our goal to better understand the microcircuitry of the brain - which cells in which areas of the brain communicate with which chemicals and in what quantities of those chemicals. The better we understood what the differences were, at a cellular level, between the brains of individuals diagnosed with a severe mental illness and normal control brains, the closer the medical community would be to helping those in need with appropriate medications. In the spring of 1995, this work was featured on the cover of *BioTechniques Journal* and in 1996 it won me the prestigious Mysell Award from the Harvard Medical School Department of Psychiatry. I loved working in the lab and I loved sharing this work with my NAMI family.

And then the unthinkable happened. I was in my mid-thirties and thriving both professionally and personally. But in one fell swoop, the rosiness of my life and promising future evaporated. I woke up on December 10, 1996, to discover that I had a brain disorder of my own. I was having a stroke. Within four brief hours, I watched my mind completely deteriorate in its ability to process all stimulation coming in through my senses. This rare form of hemorrhage rendered me completely disabled whereby I could not walk, talk, read, write, or recall any aspects of my life.

I realize you are probably eager to begin reading the personal account of the morning of the stroke. However, in order for you to more clearly understand what was going on inside my brain, I have chosen to present some simple science in Chapters Two and Three. Please don’t let this section scare you away. I have done my best to keep it user-friendly with lots of simple pictures of the brain so you can understand the anatomy underlying my cognitive, physical, and spiritual experiences. If you absolutely must skip these chapters, then rest assured they will be here for you as a reference. encourage you to read this section first, however, as I believe it will profoundly simplify your understanding.

TWO
Simple Science

For any two of us to communicate with one another, we must share a certain amount of common reality. As a result, our nervous systems must be virtually identical in their ability to perceive information from the external world, process and integrate that information in our brains, and then have similar systems of output including thought, word, or deed.

The emergence of life was a most remarkable event. With the advent of the single-celled organism, a new era of information processing was born at the molecular level. Through the manipulation of atoms and molecules into DNA and RNA sequences, information could be entered, coded, and stored for future use. Moments in time no longer came and went without a record and, by interweaving a continuum of sequential moments into a common thread, the life of the cell evolved as *a bridge across time*. Before long, cells figured out ways of hanging together and working together, which finally produced you and me.

According to the *American Heritage Dictionary*, to evolve biologically means "to develop by evolutionary processes from a primitive to a more highly organized form."[6] Earth's molecular brain of DNA is a powerful and successful genetic program - not only because it adapts to constant change, but also because it expects, appreciates, and takes advantage of opportunities to transform itself into something even more magnificent. It is perhaps of interest that our human genetic code is constructed by the exact same four nucleotides (complex molecules) as every other form of life on the planet. At the level of our DNA, we are related to the birds, reptiles, amphibians, other mammals, and even the plant life. From a purely biological perspective, we human beings are our own species-specific mutation of earth's genetic possibility.

As much as we would like to think that human life has attained biological perfection, despite our sophisticated design, we do not represent a finished and/or perfect genetic code. The human brain exists in an ongoing state of change. Even the brains of our ancestors of 2000 or 4000 years ago do not look identical to the brains of man today. The development of language, for example, has altered our brains' anatomical structure and cellular networks.

Most of the different types of cells in our body die and are replaced every few weeks or months. However, neurons, the primary cell of the nervous system, do not multiply (for the most part) after we are born. That means that the majority of the neurons in your brain today are as old as you are. This longevity of the neurons partially accounts for why we feel pretty much the same on the inside at the age of 10 as we do at age 30 or 77. The cells in our brain are the same but over time their connections change based upon their/our experience.

The human nervous system is a wonderfully dynamic entity composed of an estimated one trillion cells. To give you some appreciation for how enormous one trillion is, consider this: there are approximately six billion people on the planet and we would have to multiply all six billion people 166 times just to make up the number of cells combining to create a single nervous system!

Of course, our body is much more than a nervous system. In fact, the typical adult human body is composed of approximately fifty trillion cells. That would be 8,333 times all of the six billion people on the planet! What's amazing is that this huge conglomeration of bone cells, muscle cells, connective tissue cells, sensory cells, etc. tend to get along and work together to generate perfect health.

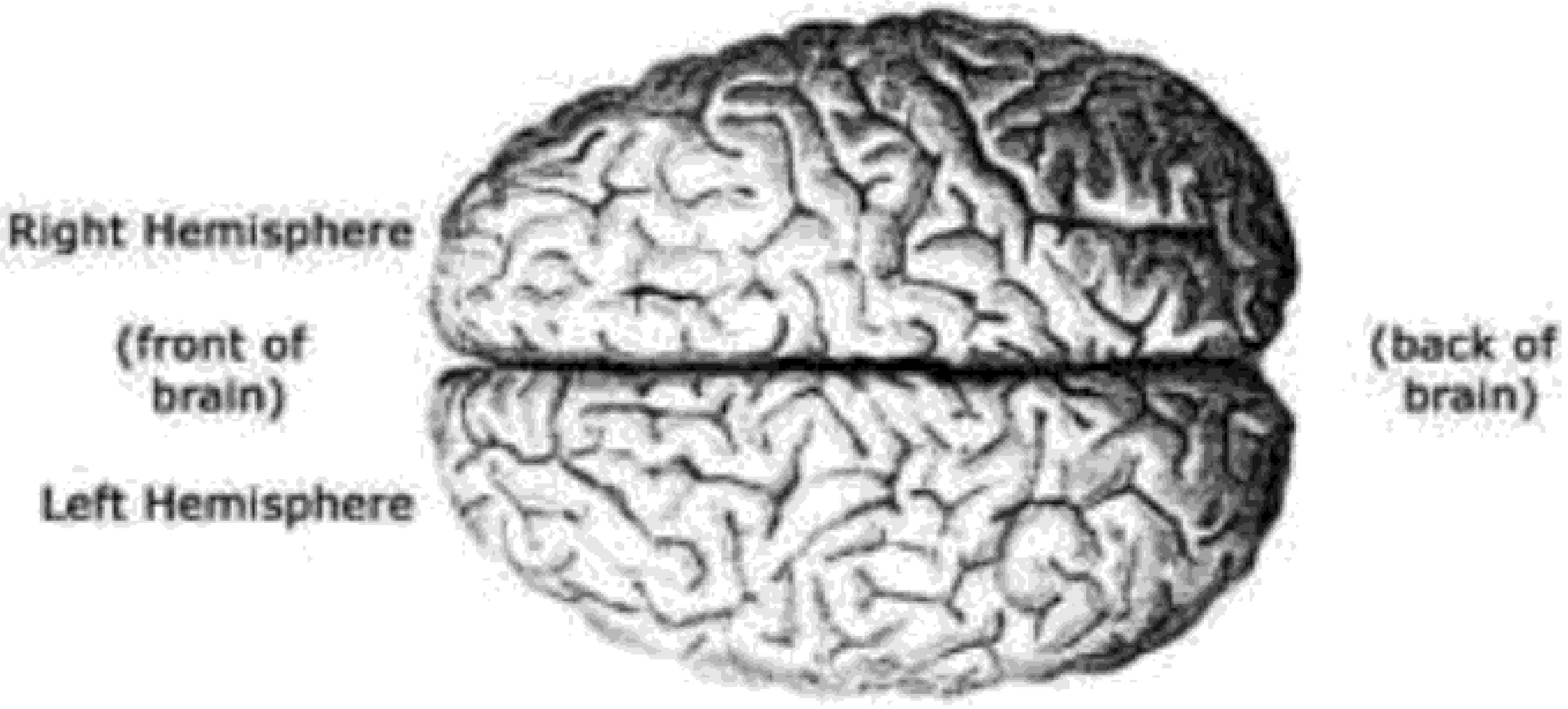
Biological evolution generally occurs from a state of lesser complexity to a state of greater complexity. Nature ensures her own efficiency by not reinventing the wheel with every new species she creates. Generally, once nature identifies a pattern in the genetic code that works toward the survival of the creature, like a blossom for nectar transmission, a heart to pump blood, a sweat gland to help regulate body temperature or an eyeball for vision, she tends to build that feature into future permutations of that specific code. By adding a new level of programming on top of an already well-established set of instructions, each new species contains a strong foundation of time-tested DNA sequences. This is one of the simple ways through which nature transmits the experience and wisdom bestowed by ancient life to her progeny.

Another advantage to this type of build-on-top-of-what-already-works genetic engineering strategy is that very small manipulations of the genetic sequences can result in major evolutionary transformations. In our own genetic profile, believe it or not, scientific evidence indicates that we humans share 99.4% of our total DNA sequences with the chimpanzee.[7]

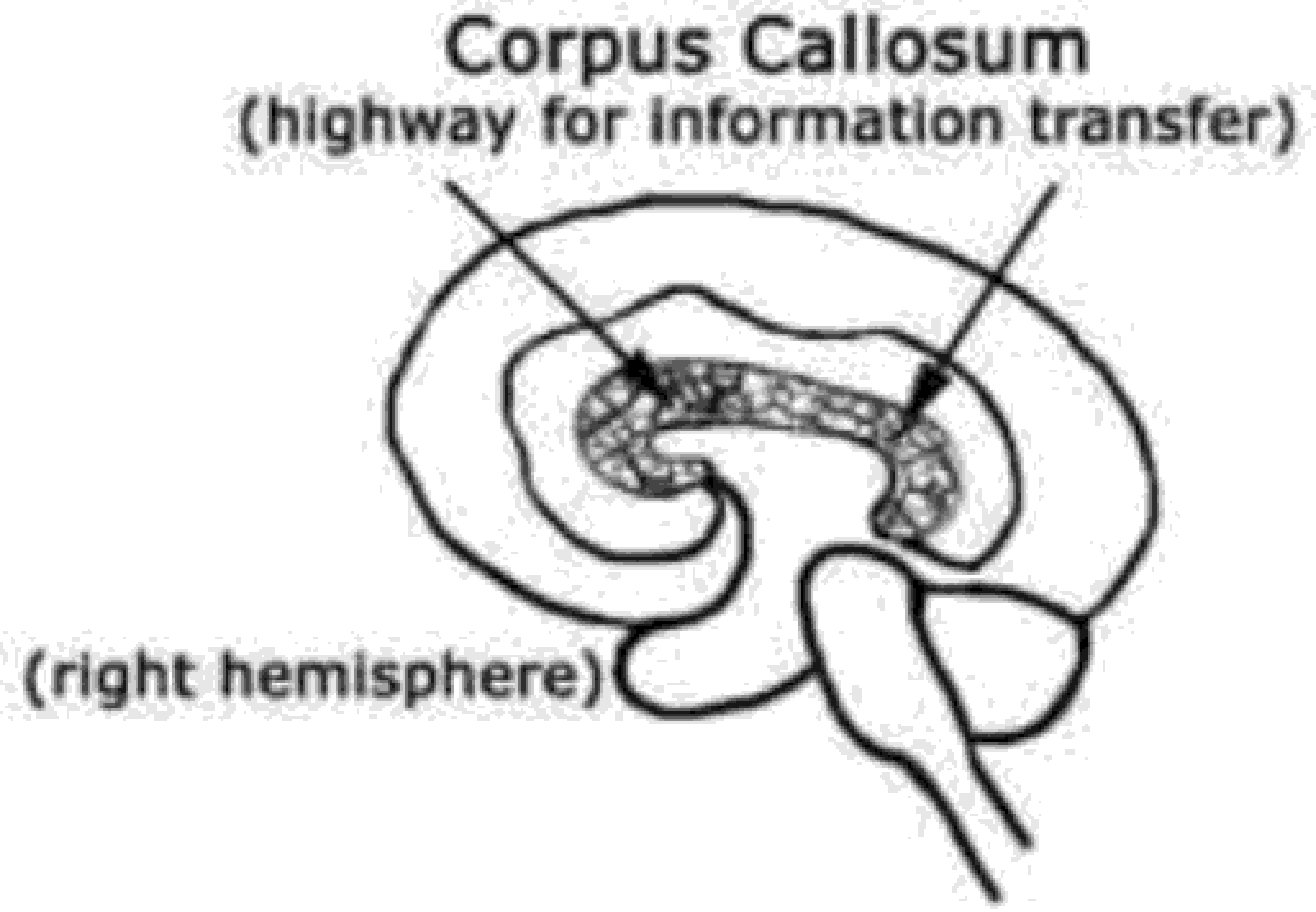
This does not mean, of course, that humans are direct descendants from our tree-swinging friends, but it does emphasize that the genius of our molecular code is supported by eons of nature's greatest evolutionary effort. Our human code was not a random act, at least not in its entirety, but rather is better construed as nature's ever-evolving quest for a body of genetic perfection.

As members of the same human species, you and I share all but 0.01% (1/100th of 1%) of identical genetic sequences. So biologically, as a species, you and I are virtually identical to one another at the level of our genes (99.99%). Looking around at the diversity within our human race, it is obvious that 0.01% accounts for a significant difference in how we look, think, and behave.

The portion of our brain that separates us from all other mammals is the outer undulated and convoluted cerebral cortex. Although other mammals do have a cerebral cortex, the human cortex has approximately twice the thickness and is believed to have twice the function. Our cerebral cortex is divided into two major hemispheres, which complement one another in function. (Note: All of the pictures in this book have the front of the brain directed to the left).


WHOLE HUMAN BRAIN CEREBRAL CORTEX

The two hemispheres communicate with one another through the highway for information transfer, the corpus callosum. Although each hemisphere is unique in the specific types of information it processes, when the two hemispheres are connected to one another, they work together to generate a single seamless perception of the world.



When it comes to the intricate microscopic anatomy of how our cerebral cortices are finely wired, variation is the rule, not the exception. This variation contributes to our individual preferences and personalities. However, the gross (or macroscopic) anatomy of our brains is quite consistent and your brain looks very similar to mine. The bumps (gyri) and grooves (sulci) of the cerebral cortex are specifically organized such that our

[4] See the end of the book for the lyrics to the Brain Bank jingle.