



Susan Frances Dunham

Beyond schizophrenia:
Michael's journey

This is a powerful memoir that captures the struggles many families encounter in helping a loved one with mental illness. Susan Frances Dunham's deep devotion to and support of her son are inspiring.

—Michael J. Fitzpatrick, Executive Director,
National Alliance on Mental Illness (NAMI)

Praise for *Beyond Schizophrenia*

“Susie Dunham’s heroic, heart-rending story in *Beyond Schizophrenia* is a beacon of light in the darkness of insanity. It shows that recovery is hard-won but possible for people who develop schizophrenia, despite a media that sensationalizes them, a society that shuns them, and a dysfunctional mental healthcare system that fails them miserably. All American Mike is more than “a perfect son.” He’s a shining example of success for 3 million Americans who suffer in silence.”

—Patrick Tracey, author of *Stalking Irish Madness: Searching for the Roots of My Family’s Schizophrenia*

“Every person in a leadership position needs to take the time to read this moving story of triumph over adversity.”

—State Representative John Adams,
Ohio House Minority Whip

“The fact that Michael bravely fought this disease, picked up the pieces and moved beyond it, should give others hope that one day schizophrenia will be seen as a treatable disease with no stigma attached.”

—Sharon Goldberg, News & Reviews Editor,
“NYC Voices”: A Journal for Mental Health Advocacy

“*Beyond Schizophrenia: Michael’s Journey* is a book that I couldn’t put down. The story of Michael’s parents Susie and Mark who support their son both in good times and bad really touched me. I really like the way the symptoms of schizophrenia are explained clearly. *Beyond Schizophrenia: Michael’s Journey* is a must read.”

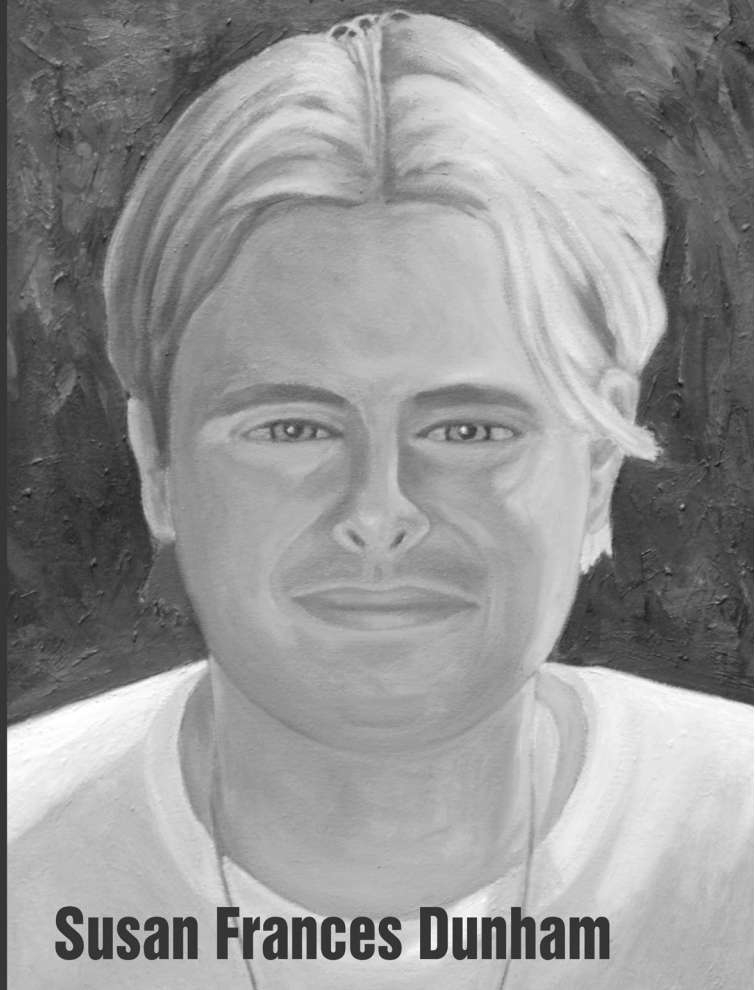
—Bill MacPhee, Founder/CEO of SZ Magazine

“Susie Dunham holds nothing back. She is so refreshingly honest and personal that I found myself wanting to give her and every family member a big hug through their tears of courage.”

—Larry Hayes, author of *Mental Illness and Your Town: 37 Ways to Help and Heal*

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Foreword

Even if you haven't had a child with a mental illness, you'll find yourself cheering Susie Dunham as she struggles to help her son Michael triumph over his disability.

Yes, I've been there with my own son John – through a son's self-doubt; through the voices in his head; through his suicide attempts; through the struggles to stay in school; through the false starts at a job. But I know as Susie so painfully discovered: There is help for those with mental illness. There's hope. Indeed, there can be triumph over tragedy. That's Susie's story.

Beyond Schizophrenia: Michael's Journey deserves to be widely read. Its insights into a dysfunctional mental health system recount an all too-familiar experience for families who struggle to cope with a child's emerging mental illness. In that respect alone, the book stands as a compelling indictment and a call to action.

Much to her credit, from the time Michael is first diagnosed when he's heading back to college and a career in acting, Susie Dunham never loses faith. She's a retired nurse who knows well how to care for other people. But Michael is her greatest challenge, even from the time he's a sensitive boy through the hospitalizations and those inevitable letdowns. As regularly as the setting of the sun, a dark curtain seems to draw close on those rare moments of promise. She and her husband Mark remain undaunted. Susie's unwavering faith inspires other family members to enlist in Michael's great battle.

She holds nothing back. She is so refreshingly honest and personal that I found myself wanting to give her and every family member a big hug through their tears of courage.

You can read textbooks and the scour the diagnostic manual, the DSM-IV. You can interview psychiatrists and therapists. But few things will give you a clearer understanding of mental illness as Susie's powerful story. Read it for the storms in the life of this family. Read it for what it teaches about character, about love. Then read this story to watch as the clouds in Michael's life slowly but surely disappear.

—Larry Hayes, author
Mental Illness and Your Town: 37 Ways to Help and Heal

Acknowledgments

This book is dedicated to Michael Francis Ralph. He is my brother, my hero, my friend in need, my keeper, and proved to be the closest person to my own mother, in her absentia. Mike saved our family in every conceivable way.

My very personal thanks go to my best friend, husband, and soul-mate, Mark. You were always right next to me. Somehow, we understood each other right from the start.

Nancy Dunham, my mother-in-law, friend, and former teacher, deserves my deepest gratitude for her unconditional help as a developmental editor.

My dear friend, Monica Heineman, graciously donated her time and skills as a professional copyeditor. Thank you, Monica! Your generosity is known to many.

Sincere appreciation is extended to Gary Wittenmyer – artist, brother-in-law, friend, and uncle to Mike – for his oil portrait of Michael, featured on the cover.

May God bless Pam McGlothlin, for her tireless efforts to provide hope, support and education to people suffering from brain disorders, their families, and the community, as a leader in National Alliance on Mental Illness (NAMI).

My final thanks go to Victor Volkman for believing in the value of my story, and gently guiding me to its completion.

Prologue

It wasn't until after two years of writing short vignettes, out of pain and catharsis, when I believed that I actually might have started to write a book. Then, I realized what I had been trying to accomplish from the beginning. I wanted to put a beautiful face that belonged to a brave, kind spirit, on a catastrophic, horrific disease. I wanted to explain quite visually: this is what schizophrenia really looks like. It is a tragic disease that doesn't discriminate between the wealthy and the poor. Regardless of race, religion, or national origin, the disease is not a rare occurrence; however, it remains poorly understood.

Michael's journey as a healthy, "All-American" kid to psychosis, and back again, is depicted through my eyes and voice, as his mother and a former nurse. My training as a nurse, to use my five senses, allowed me to document what I saw, heard, smelled, etc. But, it was my mother's instinct to write how I felt about our experiences as a family. Schizophrenia may not always present itself exactly the same way, but usually occurs in a person's late teens to early twenties. The sadness of this untimely presentation is that this is exactly the period during which young people begin to thrive and grow as young adults.

If there is possibly some universal message that my book might bring to others, it certainly isn't exclusive to schizophrenia but to all parents who must face a frightening and life-threatening diagnosis in their child. My advice would be that schizophrenia is purely and simply an organ disease. When kidney functions are compromised, dialysis is the treatment. Failure of the pancreas to produce insulin results in diabetes,

controlled with insulin given by injection. The list of treatments for dysfunctions of body organs is almost endless. Unfortunately, when the “Master Organ” of the body is compromised, because of chemical imbalances, stigma and ignorance prevail.

If it could have been possible to define the major goal of my writing over the last five years, the answer would have been resoundingly clear: Try to reach the parents of children who have been recently diagnosed with any type of brain disorder. No matter what they were witnessing, and no matter what suffering their child was enduring, recovery was possible.

Part I – Foreshadowing Events

Chapter 1 – “I Dreamed I Was a Broken Boy”

Many of the books that I read advised that it was a bad idea to bring babies or children into the parental bed to sleep at night. Babies need to find ways to comfort themselves to sleep and to gain their own independence in the world. Years later, I read that the practice of children sleeping with their parents was far more common than most parents would admit. Many mammals sleep with their offspring for years, including bears and other wild animals. Most likely, this instinct and practice is for the preservation of their young. In our case, it was for our own self-preservation.

Mike had developed itchy allergic eczema, asthma, and nasal allergies in rapid succession. Upper respiratory infections presented a continuous battle, along with simply coping with all of Mike’s allergic symptoms on a day-to-day basis. Those early years were tough on all of us for many reasons. Mark and I quickly learned that we both had to hold down decent jobs to pay the bills so that we could provide a decent lifestyle for our little boy. We understood the harsh reality of life. Our employers really didn’t care if our child was sick on any given day. They expected us to find a solution and show up for work! I confessed to my mother that we had Mike in the bed with us at night to survive.

“If you keep this up,” she said, as kindly advice, “You’ll never get him out of your bed.” *I am certain that she had some first-hand knowledge of this, as she and my father had raised eight kids*, I thought.

By four months, Mike developed “Atopic Dermatitis,” commonly known as allergic eczema. This problem escalated and became severe by the time that he was twelve months old. We tenderly bathed him in hypoallergenic soaps, later bath oils, applied topical steroids and administered antihistamines as prescribed by his dermatologist. We cut his fingernails short so that he could do less damage with his scratching, but often he dug so hard that he had taken the top layer of skin off his ankles, face, hands, behind his knees, and the inside of his arms at the bend of the elbows. Mike’s scratching was so severe that he often actively bled because his digging at the itchiness went so deep. We tried putting him in footed sleepers, thinking that it would be harder for him to get to his ankles which were the main sources of his aggravated itching. He quickly learned how to un-zip them. We tried food elimination diets and nothing helped. The skin on his fingers and ears was extremely itchy and dry, remaining cracked and open for at least nine months of the year. Summers often brought relief; but even in adulthood, winters triggered the eczema.

“Please Mikey, try not to dig,” we begged.

“I have to dig,” was his childhood response, as we re-applied the topical steroids to his skin and gave another dose of antihistamines. During peak allergy seasons, spring and fall, Mike rubbed his itchy eyes until his eyelids were raw and stripped of the top layer of skin. As they healed, they always looked scabby. His crying and frustration, as he frantically scratched at the already open wounds, was painful to watch.

The asthma began when Mike was only nine months, but the doctors didn’t diagnose it until he was over two years old. “Babies wheeze,” was what I was told as we admitted him to the hospital, at eighteen months, in acute respiratory distress. Mike wasn’t just wheezing, but grunting as he tried to get some air. His tiny ribs retracted with each labored effort. We were there with Mike in the hospital for hours. Finally, I told Mark to go

home and get some sleep because he had to be at school the next day. I realized that things had taken a turn for the worse when they took Mike from my arms into another room to perform an arterial blood gas test. I knew what they were doing to my baby as I heard him scream. They had inserted a large needle into his femoral artery, at the groin, to determine how much oxygen was in his blood. The resident doctor returned shortly and told me that he might have to start IV steroids on Mike to stop the inflammation in his lungs.

“Tell me now doctor, is our baby going to make it? I just sent my husband home to get some rest. Should I call him back?”

He hesitated and looked very troubled. “I don’t know yet,” was his response.

This was simply the first of many episodes, with all of them equally awful and terrifying. Those early years were filled with trips to the emergency room to open up Mike’s lungs. Mike’s blue lips, loud wheezing, and rib-retraction as he struggled for breath always heralded a day spent in panic, or another sleepless night. Mike grew up with an aerosol mask attached to his face, delivering relief and life-saving medicine.

The next cruel version of “The Asthma Triad” announced itself as nasal allergies. Mike’s nose ran constantly. His eyes were extremely puffy and his sinuses, inflamed because of allergens, were easy targets for infection. Once his sinuses were infected, the infection dripped down the back of his throat and inflamed his bronchial tubes, which in turn triggered his asthma. Infections became the worst culprits. One problem played off the other. It seemed that there was no winning this battle. There were specialists for all three problems. The dermatologist told us what to do about his eczema. The allergist had advice about Mike’s asthma. The newly hired Ear, Nose, and Throat doctor wanted to put tubes into Mike’s ears, but couldn’t because we could not get Mike’s asthma stabilized sufficiently to risk a general anesthetic. Sometimes the three specialists did not agree

on treatment. Still, the appointments needed to be kept. Somehow, Mark and I kept those appointments, went to work, paid for private day-care, and kept Mike at the center of our lives. What a juggling act it was!

The list of allergens that triggered all three of these problems was endless. Cats, dogs, other fur-bearing animals, weeds, pollens, molds, and foods were triggers, along with infections. Mark and I fought the good fight together, but there was always a new mystery to solve, and we tried to solve the latest, one day at a time.

“If your kid has a snotty nose,” we advised friends and family, “don’t bring him around.” Few listened. “If you have a dog, cat, or a fur-bearing animal in your house, we can’t go there.” Few understood. Often, a riddle presented itself unexpectedly.

One day, when Mike was five years old, he came home with a purple stain around his mouth. Immediately, I thought that another kind parent in the neighborhood had given him a frozen grape popsicle. Our refrigerator and freezer were always open to the other children. If we were having lunch, we invited Mike’s friends to eat with us. If Mike got a treat, we offered the same to his buddies. Perhaps another mother on the block was returning the kindness.

Two more times, the purple stain around Mike’s mouth was noticed. The second time, Mike had slightly swollen lips. We only understood this in retrospect. The third time, Mike’s lips became huge and grossly swollen.

“Mike, your lips are swollen. What did you eat? Who gave you food, and what?” Mike finally remembered that for the last three days, he had been eating mulberries from a bush behind the neighbors’ property. “Never eat them again, Mike,” we said, as we gave him Benadryl and called his allergist. This was just another day in our lives. Mulberries were clearly a new trigger to avoid. We were grateful that his throat didn’t swell shut and cut off his breathing.

Later, we tried allergy shots on two occasions. We could not complete the first round because of Mike's recurrent infections and fevers. The second round was almost completed when Mike was fourteen years old. When the first injections of the highest dose were administered in both of Mike's arms, the results were immediate and frightening. I had never seen an anaphylactic reaction in my many years of nursing, but then witnessed one. Mike developed huge hives on each arm at the injection site, had trouble breathing, and then swallowing, in rapid succession. The end result was another trip to the emergency room, with life-saving drugs given by the emergency room doctor, monitored by his allergist. We decided we'd have no more of this stuff. The risk outweighed the benefits. We'd maintain the avoidance of allergens rather than introducing them.

I look back on those years and wonder how we survived them. Mark was teaching full-time, coaching tennis for his high school, and attending graduate school in the summers. I was trying to advance my own career, one step at a time. The center of our small world was always Mike. We found ourselves not just parents, but nurses, detectives, and guardians against the awful world of allergies and infections. We never had enough money, time, or sleep. Together, we weathered the bottle feedings, diaper changing, teething, toilet training, and day care issues, along with the heartache of Mike's continuous symptoms. When we couldn't relieve his itching, stop his wheezing or wipe his nose without causing pain, which was always red and raw, he cried. In fact, he cried a lot. Sometimes, we cried right along with him. Our struggle wasn't just difficult. It seemingly went on and on forever, with only a few splendid moments of relief. Yet, it was nothing compared to what was to come down the road. Looking back, this was, frankly, just "boot camp."

In spite of all these daily troubles, our lives were indeed filled with joy. Mike was a resilient little guy, born with a sunny disposition. We thought that he belonged to us, but the truth was

that he owned both of us right from the start. We were totally smitten with his broad smile and crinkled up, mirthful, and sparkly eyes. Even as a baby and a very young child, we could see the kindness, sensitivity, and intelligence that exuded from him. We never spoke “baby-talk” to him, not just because we thought that it wasn’t the right thing to do, but because he deserved better. He seemed to understand everything that was going on around him, far beyond his years.

From infancy on, we tried all of the advised “sleepy time rituals.” Rocking, reading stories, playing soft music, and slow dancing with our child in arms were just a few measures taken to promote a good night’s sleep for all of us. We put Mike into his crib or “big boy bed,” tucked him in, and hoped for the best. In the usual event that he woke up crying because of his scratching, difficulty breathing, or was simply sick, we knew what to do. We took care of the immediate problem with medication and put him between us, in our bed. When he felt comforted, he scratched and wheezed much less. We could hear him more quickly if there was a problem, and catch a few precious hours of sleep before the next grueling day.

One significant evening such as this stands out in all of our minds. We lovingly tucked Mike into his twin bed with “Brown Bear,” his name for his brown-furred teddy bear. Mike had many bears and all of them had their own special names. He couldn’t have been more than four and a half years old at the time, as he drifted peacefully asleep, with his arm around his second oldest and favorite teddy bear. Mark and I virtually caved in, falling into an almost comatose sleep the minute we crawled into our bed. For at least four blissful hours, we had achieved deep, restful, peaceful sleep that for once had gone uninterrupted. It must have been one o’clock in the morning when our four-and-a-half-year-old came shrieking and screaming into our bedroom. He pranced around like a marionette puppet controlled by invisible strings.

“Mom, Dad, I had a terrible dream! I dreamed I was a broken boy. I didn’t have any head, hands, or feet, and I walked like this.” We both sat straight up in bed and watched in dumb awe as we tried to get our wits about us. This scene was too painful to contemplate. How could a little boy like Mike have such a terrible dream? Mark slept closest to the door and easily hoisted Mike’s “light as a feather” little body into the middle of our heavily quilted king-sized bed with his strong, young arm. Instinctively, I had raised the quilts in advance. We both wrapped our arms around our sweet little boy and tried to comfort him.

“This was just a bad dream, Mike,” his father offered over and over, as Mike shivered in fear. Mark stroked his head and patted his back.

“Mike, we’ll never let anything bad happen to you. Dad and I will always be there. I promise.” After much talk about bad dreams and constant reassurances, the three of us fell asleep in an exhausted embrace, but none of us ever forgot that night.

Some things are so horrible that you could never “dream” of them in advance. These things are absolutely inconceivable, unthinkable. We have control over many things in life. For those things, we must take full responsibility to avoid calamity. Tragedy or an unhappy fate is self described and unavoidable. Mark and I convincingly made promises to our only child on that night that we couldn’t keep. Years later, Mike became a broken boy.

Chapter 2 – When Did This Start?

Any parent who has witnessed the tortures of schizophrenia will ask themselves the following questions:

“Why didn’t I see what was coming?”

“What were the warning signals?”

“What could I have done to stop this from happening?”

“What could I have done to protect my baby?”

The clues and answers only became understood after the disease had fully manifested, but they had indeed been there for a while. I had seen changes, but they were insidious and confusing. I had asked many questions, but the answers I received seemed logical. I thought that something was not right, but also believed that nothing was terribly wrong. The knowledge that I received by attending NAMI’s “Family to Family” program, two years later, convinced me that Michael had exhibited many “classic” onset symptoms. His early symptoms were:

- Anxious moods
- Change in sleep patterns
- Weight loss
- Withdrawal, decline in function, and lack of attention to personal hygiene
- Illogical thinking and lack of insight

There is always a “Prodromal Stage” in schizophrenia. A *prodrome* is a symptom indicative of an approaching disease. For example, in the disease of measles, a person will first have sensitivity to light before the rash and other symptoms appear. I saw the changes, but confused most of them with the side-effects