

Loving a Sibling with a Chronic Illness

By Trudelle Thomas, NAMI Leadership Alliance Donor

Jennifer tap-dances across the stage in her sparkly dress. Even though she's just a sixth-grader, she's been invited to perform in a high school production of *Crazy for You*, with its lively Gershwin songs.

My niece, Jennifer, holds a special place in my heart because she is the only child of my only brother. I see my Billy in her mischievous brown eyes and her sense of fun.

Billy was born when I was around Jenn's age, and I formed an unbreakable bond with the lovable brown-eyed "squirt." As he grew up, Billy earned the nickname "Chimp". No one can remember when we started giving him birthday cards that featured a grinning chimp, but I'm sure it had something to do with his talent for mimicry—of animals, celebrities and more. As the oldest sister in our big family, I became Billy's second mother, his protector.

Billy died in his sleep six years ago, not long before his 44th birthday. His death was the result of heart failure, caused in part by long-term use of antipsychotic drugs. For nearly 25 years, he'd been working on his recovery with heroic determination.

Billy's mental illness struck the year after he graduated from high school, during his first year in the U.S. Marines. In



Trudelle Thomas

1980, schizophrenia was even less understood than it is today. It was something most people whispered about or mocked, if they spoke of it at all. Thanks to early intervention, support from NAMI, a close-knit family and his own fighting spirit, Billy learned to manage his illness.

As a sibling of a person living with serious mental illness, I faced my own set of challenges. I wanted to keep our close bond but wrestled with feelings of grief, worry, frustration and guilt. Even though I knew better, I felt guilty for not protecting him. I worried terribly that he would end up sleeping under a bridge. For a long time, the way I expressed my caring was by giving him advice: "Go back to school!", "Don't eat that Cheeto!" and "Stand up straight!" I also became an overachiever, trying to compen-

sate for my family's heartache.

Years passed before I encountered the concept of "unconditional positive regard"—the idea that *all people* need and deserve unconditional acceptance. When I first heard this phrase, it was as if a light bulb lit up. I realized that I'd been treating my brother as a problem or a patient rather than a person deserving unconditional acceptance.

Family patterns are hard to change, but I made up my mind to change the way I interacted with my brother. I stopped acting like his second mother and started to become his friend. Unless asked, I gave no advice. I stopped focusing on his illness

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Darkness to Light

By Albert Hsu, NAMI Fairfield



Albert Hsu

The first time I tried to kill myself, I was 11-years old. Suicide always lurks in my consciousness as the final option. I don't know if other people think that way. I knew something was wrong early on. I was functional—despite soaring highs and debilitating lows such as violent outbursts, often followed by equally violent beatings, and a hyper-sexuality that developed

after a neighbor's daughter molested me.

My inability to be in stable, intimate relationships from my teens on was driven by alternating highs and lows. I sought help; seeing over 10 therapists. Nothing helped. Eventually, I married a woman thinking it could help. In time, that faded and again my outbursts and hyper-sexuality continued. My wife and children withdrew from me as I cycled.

My career was successful though, especially in the years before I imploded. My highs fed an aggressive drive, resulting in positions of increasing responsibility and salary. Even then, the signs were there. My jobs were short-lived as I became increasingly unstable. Being in the highflying investment world masked this and as my compensation grew, it fed my highs. I spent money like water.

When I was 39-years olds, I began a three-year affair that only exacerbated my disorder. My family life was disintegrating and one night, after a particularly violent outburst, I loaded a rifle threatening to shoot myself. I remember thinking that I didn't want to leave my brains all over the dining room so I should do this elsewhere. My wife called the police who took me to a local hospital where the staff did a perfunctory evaluation and released me that night. For the first time in my life, I accepted that I needed psychiatric help. I met a local psychiatrist who loosely diagnosed me as having bipolar

disorder and prescribed a low dosage of a mood stabilizer.

A few months later, my mistress broke off the affair, sending me into a tailspin. I couldn't accept it. I became increasingly paranoid, having more violent outbursts toward my family and business partners. I entered a prolonged depression and, over the next year, sank progressively lower until I hit rock bottom. In November 2006, I solicited someone over the Internet to have my mistress kidnapped. Fortunately, I was apprehended, pled guilty and sent to prison for almost three years. Prison psychiatric treatment is poor, and my therapeutic needs went unmet. Once released, I obtained good medical help. I began seeing a competent psychiatrist and a therapist on a regular basis. I received a much deeper diagnosis of my bipolar disorder and my medications and dosages were adjusted until, we found the right combination.

My kids stopped communicating with me, my wife divorced me and I lost everything that I thought defined me. However, in the process of recovery, I obtained stability. My ex-wife and parents helped get me back on my feet and my children and I are repairing our relationships. I started attending Quaker meetings and I give back to the community as best I can. With these stabilizing influences, my highs and lows are under better control. Sometimes, I wish I still had those great highs but now I will always have to be diligent and watch for my warning signs because I can't go back to the lows of my past.

Only in the past few years has the wider diagnosis and acceptance of bipolar disorder caught the public's awareness. The symptoms and behaviors have garnered more attention from the medical community making it easier to identify and treat the disorder. The stigma surrounding mental illness has lessened in recent years, but still exists among the wider population. Education, time, courage and acceptance are the best prescription.

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Overcoming the Shame and Stigma

By Stephen O. Akinduro, NAMI Columbus



Stephen Akinduro

When I was a teenager, I wondered if other people were in on some big secret that they were not sharing with me. Why wasn't everyone just as miserable as I was all the time and what was the secret to their joy? Was I the only one wearing the mask I had to wear every day just to survive? After unsuccessfully trying to overcome my misery with willpower,

sexual promiscuity, self-destructive habits and even religious fervor, I had virtually lost hope of ever experiencing a fruitful and joyous life. At my worst, my depression was so severe that I likened it to a vacuum cleaner that sucked out 99 percent of the joy and hope out of your soul, leaving you just enough to survive but not enough to enjoy living.

Depression is a living hell, like having to experience the worst grief you've ever had to face, day after day. "When will it end?" was the question I kept asking myself. I quickly came to the conclusion that suicide would be the only way to end my misery. But something held me back—not just the fear of death, but also knowing that taking my life would bring an immeasurable level of pain to my family and friends. My family had, after all, been down that road before. I lost my mother to suicide when I was 8-years old. She was only 34-years old when she died and had struggled with clinical depression for most of her life. Her depression was exacerbated by the alcohol she used to try and drown the pain of a very abusive relationship with her husband, my dad.

I was very reluctant to get treatment because of the shame and stigma associated with mental illness. I had associated mental illness with the word "crazy" and I didn't want that label. I realized that the stigma was even greater in the African-American community, where I had heard statements like, "Oh, mental illness is just something white people use to excuse bad behavior." My dad is Nigerian and I lived in Nigeria with him for 15 years, moving there from Boston in the late 1970s. While I was there, I realized that the common belief was that religious fervor and dedication to God were all I needed to cure any ills. I dove headfirst into my Christian faith, getting re-dedicated to Jesus, re-baptized and becoming very active in lay ministry. After none of this

brought any lasting relief, I became so disillusioned with God I almost lost my faith completely.

I received my initial diagnosis of major depression after a suicide attempt, not too long after graduating from college. My current diagnosis is bipolar II depressive type. It has taken me losing jobs, failed relationships, financial woes (including bankruptcy in my 20s), and so many other negative effects from my untreated disorder to finally realize that I needed to stick with treatment. I am gradually starting to feel less ashamed of struggling with a mental illness, having learned that I am not my disorder. I am a human being first, who happens to struggle with an illness. I am no more defined by my illness than a person with high blood pressure is not defined by that condition.

NAMI has been a priceless asset in my recovery process. Before I found NAMI, I thought I had to suffer in silence because I was rarely around people who were authentic enough to share their own struggles with mental illness. NAMI has shown me that mental illness does not have to be a death sentence and it is not anything which I should be ashamed. Mental illness affects people from every walk of life, race, gender, creed and sexual orientation. I can honestly say that NAMI has been a crucial lifeline in my recovery because mental illness seems to be one of the few disease categories where stigma still unfortunately prevails in our society.

Today, I am happy to say I pay it forward as a NAMI In Our Own Voice presenter and a Peer-to-Peer mentor. Anyone who struggles with mental illness should get plugged into NAMI. It will really help you along your journey of recovery.

Share Your Story

Your stories of hope and recovery from mental illness can help others. Please send yours to Darcy Taylor at DarcyT@nami.org and have it published in upcoming editions of *NAMI Voice*. We all have different experiences in life and that is what makes the NAMI community so strong and diverse. NAMI will edit your story for length and clarity, if needed.

(Please keep your story to 500-800 words and send a high-resolution photo of yourself along with the article.)

What NAMI Means to Me

By Martha Pillow, NAMI Roanoke Valley



Martha Pillow with Robin

I have a mental illness called schizoaffective disorder.

For more than 25 years, I lived in my own nightmarish world of hallucinations, delusions and paranoia. I was afraid of almost everyone and almost everything. I existed in my own personal hell.

For the past four years my life has changed for the better. I am presently on the Board of NAMI Roanoke Valley, the Roanoke Valley Local Human Rights Committee and the Board of the Virginia Office for Protection and Advocacy (VOPA). I'm also a NAMI In Our Own Voice presenter.

How did I get to this point in my life? The answer is: the right combination of things finally clicked for me—namely, a psychiatrist and a therapist I can trust and work with, the right medications, my own hard work, and the support of others, especially of NAMI.

What would I have done if NAMI hadn't been there? NAMI offers support, education and advocacy for people with severe mental illness. NAMI was the first organization where I learned that I could experience recovery. Aside from the

tremendous support I received from the friendly, accepting folks I met at meetings, I learned about mental illness and the various services available to me in the community and beyond.

One of the most empowering things NAMI did for me as I began to turn the corner in the progress of my illness toward recovery was to make it possible for me to attend an In Our Own Voice training session. I can honestly say that by making the decision to attend the NAMI training, I changed my life.

Before the training, I was a painfully shy person. I would never have thought that I could stand before a group and share my story. I am more outgoing now and I am no longer afraid of talking with people I don't know. I feel empowered and self-assured in a way I have never been before. I have NAMI and In Our Own Voice to thank.

My becoming more outgoing is only an outward change. NAMI also taught me strength and self-worth and to face a world where others may not be so accepting of those with a mental illness. I have fought a battle to get where I am and I am proud of each and every accomplishment, large and small. I've been in recovery only a short while and struggled every step to get where I am today. I have pride in myself no matter where I am along my recovery journey. NAMI taught me that.

To learn more about NAMI's In Our Own Voice program, visit www.nami.org/IOOV.

Loving a Sibling cont. from page 1

and instead made a conscious effort to talk about my own life, my own joys and sorrows, even asking his advice from time to time.

Most of all, I stopped feeling guilty that he had a chronic illness. I came to accept that Billy had been given a very tough path to walk, but it was his path. He had his own path and I had mine. We both learned to be companions instead of helper and helpee.

The self-help book *The Dance of Anger* was a great source of wisdom to me. Author Harriet Goldhor Lerner calls changes like the one we made "tasks for the daring and courageous." She explains that a person who is an "over-functioner" (like me) can cause others to remain "under-functioners" and actually block them from becoming more capable. As I learned to relate to my brother in this new way, I began to see more clearly the things I loved about him, especially his courage. More impor-

tantly, the change empowered Billy to take greater responsibility over his own life. Before his death, he was finally living the independent life that he had wanted for so long.

Although Billy has been gone seven years, we still speak of him often. What we remember aren't the sad times but the joyful ones, like how much Billy enjoyed simple pleasures like dancing or singing karaoke. His silly "chimp grin" and how he delighted in his pet parakeets. His passion for old movies and rock music. His patriotism and love of family. These are the stories we tell Jennifer about the father who died when she was so young.

Watching Jennifer dance across the stage, I am so grateful that she is a part of our family. Billy may not be with us in body, but he lives on in his daughter. We will make certain Jennifer knows what a remarkable person he was.

Chimp grin and all.

The Hearing Voice Approach

By Ron Coleman, Working to Recovery, Ltd.



Ron Coleman

In early January 2012, Paul Baker (an associate at Working to Recovery) and I were invited to run a seminar exploring the issue of people who heard voices. The meeting was on a Saturday and, I must confess, we did not expect many people. To our surprise the room was full—over 80 people waiting to hear us speak about the

impact that hearing voices can have on a person's life.

After the meeting, which had been organized by NAMI Pennsylvania Montgomery County, Paul and I reflected on the day. This led to a discussion with Karen Taylor, my wife, and Sandra Escher of developing a one-day workshop especially for friends and family members of people who have been diagnosed with mental illness.

Yet the more we talked, the more we realized we had focused all our energies on voice-hearers and practitioners and little time on working with families and friends in an organized way.

That day was a wake-up call for us. As we talked through the issues raised that day, a framework for working with families started to emerge. We identified six main themes of the framework:

- 1) Giving and receiving support
- 2) Action plans for helping a family member or friend who hears voices
- 3) How to relate to a family member/friend hearing voices
- 4) How to reassure a family member/friend hearing voices
- 5) Helping the family member/friend who is hearing voices
- 6) The provision of good information

Many people who hear voices have told us of the importance of friends, family and partners in helping them develop good coping strategies for dealing with intrusive and distressing voices.

It is important to the person hearing voices that you believe what they are telling you. Tell them you would like to hear more about it and be ready to listen. Ask them a number of questions that are non-threatening about their voices. How

long they have been hearing them? How many voices do they hear? Who or what are they? Do they have names? What do the voices talk about? Family members or friends can offer a lot to the voice hearer through good listening skills. This encourages the voice hearer to express their feelings.

Remember laughter is okay. You do not always have to be serious to show that you care and doing something light-hearted can help ease tension. Another approach is to give the person who hears voices space and time alone when they need it.

Some people may feel this is obvious guidance but when we talk to family members they tell us they feel helpless with their loved ones' voices and choose to call a psychiatric team or use medication that has been left for this purpose. Although these interventions can be helpful in the short-term, the reality for many families is that they get stuck in a cycle that is just as distressing for them as it is for the person hearing voices.

This helplessness is unnecessary and it is possible to develop ways of working within the family context to allow families to reclaim their lives. Families have an expertise to bring to the table and their contribution can greatly help a persons' recovery journey. By offering a new perspective on what the hearing voices experience represents and how families can help their relative or friend cope with these distressing voices, we see that family members, as well as voice-hearers, develop new and empowering ways of reclaiming their lives.

It is time to focus on family and friends as an integral part of the process in helping people with psychotic experiences. In order to achieve this, we need to help them gain the knowledge and tools to be confident in the process.

For more information please visit:
www.workingtorecovery.co.uk

*Please make sure not to miss the following session at the NAMI 2012 National Convention on the afternoon of Wednesday, June 27th: **The Voice Inside: An Introduction to the Hearing Voices Approach***



Register Online Now!

Go to www.nami.org/convention for more info!

Come join us for the 2012 NAMI National Convention in beautiful Seattle!

The convention will be held at the Sheraton Seattle! Make your reservation early either online at www.sheraton.com/NAMIHotselReservation or call (888)627-7056 and mention the NAMI National Convention.

My First View of Mental Illness

By Judy Beckman, NAMI Greater Toledo



Judy Beckman

I was 7-years old when I first saw mental illness. There was a different person inside my mother's body. Mom was doing things she didn't do before. She began dressing up and taking walks around the neighborhood. Sometimes, she took us with her. When I told her I was going outside to play, she took me by the hand and escorted me to the yard. In the house, she laughed

and talked as if she were at a party with people I could not see.

One day, mom visited the priest at the church across the street. This caused my father to be called home from work and ordered to take care of his family. Dad dealt with this by telling us to watch mom and not let her go for walks. Children watched the mother instead of the other way around.

I knew mom wasn't going to get better unless she got medical treatment. I often ran off to the park and desperately prayed for her. I cried that the mother I knew was gone. Although this different person was very nice to me, I wanted the old mother back.

One day my sister, my father and I went upstairs to check on mom as she was resting. We found her face down on the floor, unable to get up. As he went to the phone to call emergency services, dad excitedly ordered us to pray for our mother because she may die. Shocked and stunned, we got down on our knees, praying every prayer we knew, pleading with God to save our mother's life.

This incident caused mom to be hospitalized for several weeks. My sister and I were put in charge of housework and watching our younger siblings. While I was relieved mom was finally getting medical care, I continued to be upset about my own losses. Housework and babysitting took away large chunks of playtime. The house was lonely without mom's reliable, constant presence.

Mom's mental illness pervaded my entire childhood. Typically, there was progressive recovery and then some relapses. Money was tight in a large family of six children, and medical care was often neglected. Dad gave doctors good reports in order to get mom back home to take care of the family, but she was not totally her old self. She kept up with housework, cooking and watching the children, but she was preoccupied in a

world of her own, exhibiting strange behavior at times. Gradually lucid moments increased and illness decreased, whether or not mom was taking medication for her diagnosis of schizophrenia. Mom often had an unfocused, expressionless stare. She was unable to be nurturing or affectionate and to handle our changing needs as we grew. I knew mental illness took away parts of my childhood that others took for granted.

Mom's first psychotic break happened a year before I was born. It occurred in 1950 after she gave birth to twins. She could not care for them and had to be transported to the psychiatric ward where electroshock therapy was administered. In a few months, she was reacquainted with her environment and resumed care of the family. Later episodes were treated with psychiatric medications. Mom always cooperated with medical care when it was obtained for her. She responded well to prescribed drugs. Even though she was told that she would need to take pills all her life, she discontinued them after long periods of feeling okay. Eventually, she did not relapse. In later years, the doctor prescribed an antidepressant to help her through stressful situations. This prevented her from ever having another total breakdown.

I am telling my mother's story to do my part in NAMI's mission of unmasking mental illness. My mother represents a picture of mental illness that does not get much publicity. She and millions of others who live with mental illness are not violent or noncompliant with treatment. Mental illness is a biological brain disorder that has nothing to do with character. Like other illnesses, it requires medical treatment for healing. Although family love and support are good things, they are not enough to return a loved one to healthy functioning. Modern research and treatment methods give more hope than ever for overcoming this terrible disease and restoring what was lost to individuals and families. I pray that my mother's story will motivate others to seek immediate treatment when having symptoms of mental illness.

Donate your Vehicle and help NAMI

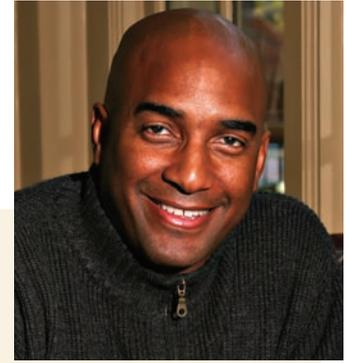
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Vehicle Donations

By Darcy Taylor, NAMI Director of Constituent Relations



Many people have asked me, “What makes NAMI relevant?” For more than 32 years, NAMI has been focused on supporting and representing individuals and families affected by mental illness. Today, we continue providing NAMI’s outstanding educational and support programs to children and adults in every community, city and state across the country. We continue being a trusted advocate by fighting to bring about changes in policies that address the barriers to quality care. When people talk about NAMI, you hear them say things like: “What an outstanding organization”, “NAMI gets things done” and words like “They care.” This is why we exist.

None of this would be possible without the support of all our donors, particularly our Leadership Alliance Donors. NAMI established the Leadership Alliance Donor Club in recognition of its top supporters. For many years now, they have been the bedrock of our fundraising, for which I am truly grateful. I would like to extend a warm welcome to our newest Leadership Alliance Donors —those who have recently given a gift of \$500 or more to NAMI for the first time. You are now part of a very special group within NAMI’s family and friends. Our gratitude goes out to all of you—our newest Leadership Alliance Donors as well as those of you who have supported NAMI for up to 32 years. You each play a critical role in NAMI’s success of its mission to ensure that people living with mental illness can find help and find hope.

Among the most popular Leadership Alliance benefits offered is our “by invitation only” recognition event held each year at the NAMI National Convention. 2012’s event, a reception in Seattle Washington’s landmark Space Needle, is shaping up

to be a wonderful evening filled with picturesque views of downtown and the mountains beyond. We hope you will all have a chance to join us at this special event.

Due to the support of our Leadership Alliance Donors, we can say that NAMI’s accomplishments speak loudly. We are fostering a more financially secure, technologically informed and service-oriented organization all while helping individuals living with mental illness, their families and NAMI members live more satisfying and rewarding lives. Though 2011 was a difficult year financially for many non-profits, the support of our Leadership Alliance Donors helped us make it through. We would like to invite all of our donors to become a part of our Leadership Alliance in the coming months. For more information about this special alliance, contact Jennifer Barton at jenniferb@nami.org, (703) 516-7970 or (888) 999-6264, ext. 7970.

Once again, I would like to join NAMI Executive Director, Mike Fitzpatrick, in expressing our gratitude for all your continued support of our work.

Sincerely,
Darcy Taylor, Director of Constituent Relations

A Doctor Learns to Treat Mental Illness

As a fourth-year psychiatry resident at the University of Cincinnati, I look back on my residency to see the growth I have gained in learning to treat mental illness and, most importantly, how to help people. I can remember the first day I was on call in the psychiatric emergency room. It felt uncomfortable and scary to interview very sick patients through the night, knowing this time my decision affected someone very vulnerable. Reading the stories of survivors of mental illness in the *NAMI Voice* reminds me that there can be positive outcomes from the work of psychiatrists and all others in the mental health field. Congratulations to NAMI for providing a stabilizing backdrop for patients and families! These stories also remind me of how much work there is yet to be done. Could there be a future with no mental illness? Though I will be graduating from my residency and practicing psychiatry shortly, I look forward to the day when I am “out of a job” and no psychiatrists are needed ever again because there are cures for these diseases.

Amy Shah M.D.
NAMI Northern Kentucky

NAMIWalks Celebrates 10 Years!

As NAMIWalks celebrates its 10th anniversary in 2012, we are proud to be the largest and most successful mental illness awareness event in the United States. As we move rapidly into our spring walk season, we have a lot of successes that we would like to share with you including an increase in fundraising and an exciting new NAMIWalk website.

- 1) 2012 NAMIWalks Fundraising Total (4/13/2012) **\$2,672,373** (up 8.2 percent from 2011)
2011 NAMIWalks Fundraising Total (4/15/2011) **\$2,469,303**
2010 NAMIWalks Fundraising Total (4/5/2010) **\$1,751,418**
- 2) We are happy to announce the launch of our new NAMIWalks website in May 2012 for use by 40 fall NAMIWalks that will be fully integrated into the social media world.
- 3) Both NAMI and NAMIWalks has raised awareness by generating over 228 million print impressions and over 47 million radio and television impressions in 2011 and we expect that number to increase significantly in 2012.
- 4) We are thrilled to announce that NAMI Massachusetts is on track to be our first walk to raise more than \$500,000 with a single event!
- 5) Introducing, our first ever NAMIWalks National Sponsor: Universal Health Services (UHS). UHS is one of the nation's largest and most respected healthcare management companies, operating through its subsidiary acute care hospitals, behavioral health facilities and ambulatory centers nationwide with more than 65,000 employees.

To find out how you can join in the fun of NAMIWalks in YOUR area, please visit www.nami.org/walks.

Warren Karmol
Director, NAMIWalks



NAMIBikes:

New NAMI Program Attracts a New Audience



Our NAMIWalks campaign is one of the most successful grassroots campaigns in the country, and NAMI has been hosting great outdoor events and fundraisers for 10 years. As leaders and community organizers we have great experience. We feel it's time to take it

up a notch and bring in the bike!

A new campaign from NAMI, the NAMIBikes program, aims to engage a young and active

demographic and publicly address the stigma and stereotypes that surround mental illness. Through a national series of bicycle rides and bicycling events, we will introduce a new group of people to NAMI, open their eyes to mental illness and educate them on why what we do is so important. We will empower people, move them to action, and turn a tide of perception with a simple tool: the bicycle.

With great feedback from our 2011 pilot sites in Florida and Arizona, NAMI State Organizations around the country are being lined up for fall 2012 and spring 2013.

We hope to see you on the road! For more information on this exciting initiative, visit www.NAMIBikes.com