

## The Family Burden of Schizophrenia

Providing care for one of the estimated two million people in the United States who suffer from schizophrenia can be overwhelming at times. Caregivers report experiencing increased stress related to caring for a loved one, including hurtful feelings of stigma associated with the illness, financial concerns and anxiety about the future care and welfare of a loved one. Caregivers may have decided to quit work for some time or find another form of employment more suitable to providing the necessary support. Their ability to spend time doing things they love such as social and leisure activities may be negatively impacted. Other family members may feel neglected by the time spent caring for an ill family member because caregivers (often parents) may not be able to spend as much time with the other children as in the past.

These are just a few of the ways that caregivers report feeling the changes which disrupt their lives as a result of looking after a family member afflicted with schizophrenia. The impact of these changes is commonly referred to as family burden. **This article seeks to offer some helpful insight and advice to assist caregivers in their role of helping a family member with schizophrenia.**

**First** and foremost, avoid the blame game. It is natural to question the nature and causes of the illness. Schizophrenia is a neurobiological brain syndrome that is likely caused by a disruption of brain development during fetal life.



**Mary Beth De Bord, JD**

**Second**, educate yourself on the nature and symptoms of schizophrenia. Another helpful resource is *Surviving Schizophrenia* by Dr. E. Fuller Torrey. Knowledge is power and knowing what to expect in terms of symptoms and treatment is crucial to a loved one's recovery. Patients are often unable to process the information about the nature of their illness and the recommended treatment during the initial onset of the disorder. Thus it is critical that a caregiver be informed and be able to advocate on a patient's behalf. Thorough knowledge of schizophrenia can empower you to care for your loved

one and to educate others about the nature of the illness and to eliminate the unjust stigma associated with the disorder.

**Third**, take care of yourself. Although it may seem implausible and difficult, it is critically necessary that you get proper sleep, sustenance and support. Getting between seven and nine hours of sleep a night will help recharge your body and allow you to be better prepared to help your family member. Eating a healthy diet will keep you strong and resilient and give you the necessary energy to get through your day. And finally, ask for support from family, friends, coworkers and others. You may wish to attend programs which connect you with other caregivers or seek help from a licensed therapist. Whatever support you choose, be kind to yourself and give yourself the time you need to adjust and thrive.

The good news is that there is hope for those struggling with schizophrenia. Although it has a chronic course, schizophrenia is a treatable disorder. Those afflicted with it may recover and live fulfilling lives with proper treatment. The role of caregivers is instrumental in the recovery process and caregivers can feel a great sense of gratitude and accomplishment by assisting a family member in their journey of recovery. Focusing positively on the recovery process is critical not only to the recovery of a family member suffering with schizophrenia but also to the health of caregivers and other family members.

CURESZ.org offers many helpful videos and articles to help cope with these issues.

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### WhatSZ IN THIS EDITION

**Survivor Highlight:**  
**William Jiang, MLS**

Pg 2

**CureSZ Brain Facts**

Pg 2

**An Interview with**  
**Dr. Erik Messamore, MD, PhD**

Pg 3

**How to be a Featured**  
**Schizophrenia Survivor**

Pg 4

**Video Highlight: Delusions**

Pg 4



# SCHIZOPHRENIA SURVIVORS



## The Story of William Jiang, MLS



**William Jiang, MLS, Librarian, Writer, Schizophrenia Survivor, and More**

Sometimes it is the blind man who can see most truly. I feel such is the case with me, William Jiang. I suffered a severe paranoid psychotic break from reality at nineteen years of age, while I was a sophomore at SUNY Stony Brook University. I was devastated. While in the hospital, I began the medication Navane. It helped, but times were different. Nobody leveled with me. Nobody told me I was struggling with paranoid schizophrenia. Nobody told me to continue taking the medicine either, or I would suffer a relapse and my psychosis would get worse. Indeed, my psychiatrist took me off the antipsychotic medication that kept neurodegeneration at bay, and I subsequently became much sicker and less functional. This was 24 years ago. I take a higher dose of medicine now than I did back then.

Doctors give much better guidance today. Psychiatry has evolved. Let me tell you that there is a difference between people who have only had “one break” and those who have had “multiple breaks.” It is far better to keep taking the medicines, even at a low dose, than getting off of them completely and risking being a multiple break patient. Today, many individuals with schizophrenia begin injectable medications which keep their symptoms at bay at a time when they may refuse medication or forget to take it.

In any event, thanks to effective treatment, I continued my university studies at Stony Brook. Over the next year, I would be hospitalized two more times. Fighting the odds, I graduated with a Bachelor of Arts degree in English Literature in 1994. I went on to complete my Master's of Library Science degree from Queens College in 1999. I worked as a professor in 2001 at Kingsborough Community College. I was a Medical Library Chief with Columbia University from 2004 to 2011, during which time I published a memoir titled *A Schizophrenic Will: A Story of Madness, A Story of Hope*. After leaving Columbia Psychiatry I have published 62 more books, mostly about mental health and wellness in English, Spanish, French, and Portuguese.

For those who need medicine for psychosis I recommend many things, in my book *Guide to Natural Mental Health*, but to prevent tardive dyskinesia, which happens often in long-term antipsychotic treatment, I heartily recommend taking a vitamin E supplement to lower your risk.

I invite you to check out my author blog and books at: [mentalhealthbooks.net](http://mentalhealthbooks.net)

## CureSZ Brain Facts

by Henry A. Nasrallah, MD  
CURESZ Scientific Director

Two brain regions are associated with the major cognitive challenges in schizophrenia: the frontal lobe and the hippocampus formation. Both regions have been shown to be hypoplastic, which means they are not fully developed, and probably have anomalous connectivity to other brain regions. The frontal lobe is the “CEO” of one's life, the executive control center, making decisions, planning ahead, learning from past mistakes, and adjusting to change. The hippocampus is the major memory center of the brain, especially for the (very short) working memory. Preventing relapses may help avoid further cognitive impairment in persons with schizophrenia.



# EXPERT INTERVIEWS

An Interview with

## Dr. Erik Messamore, MD, PhD

Part 2 of 4

### **Q** Clozapine is sometimes called a “wonder drug.” Do you agree with this?

I'm not a fan of labels like “wonder drug” for medications. The most successful outcomes are usually the result of a treatment approach that combines multiple approaches like psychotherapy, environmental modification, bolstering social support, and helping people to reconnect to the things in life that give them meaning, purpose, and joy. Labeling a particular medication “miraculous” creates a risk of over-focusing on one approach even when others are also valuable.

On the other hand, clozapine does appear to have a higher level of treatment effectiveness than any other medication for schizophrenia and can be uniquely effective in cases where other medications have failed. The average patient will have spent several years dealing with inadequately effective medications before she/he is offered clozapine. To someone who has struggled with symptoms for so long, finally being on a truly effective medication certainly can feel miraculous.

### **Q** Why do some doctors and psychiatric nurse practitioners not have much experience in prescribing clozapine?

Generic forms of clozapine became available in the late 1990s. When a drug becomes available as a generic, it is no longer actively publicized by a drug company. There is no more advertising in professional journals, no promotion at conferences, no one coming to your office to help answer questions. Around the same time, several other new “second-generation” or “atypical” medications were coming onto the market, and these newer medications were extensively promoted by their manufacturers. Corporate promotion of clozapine vanished while publicity for less effective newer drugs flourished.

You would think that medical schools and the programs that train psychiatrists would pick up the slack. But this did not happen across the board. The national organization that dictates the training curriculum for the country's residency programs does not specifically address clozapine instruction. Whether a particular training program offers clozapine-specific training is up to the individual program. It's not a national standard.

So it is entirely possible for a new psychiatrist to enter practice with no firsthand experience to prescribe clozapine and to observe its often-remarkable benefits. Absent from this experience, a newly-minted psychiatrist may enter practice unprepared to use this medication. The situation is the same for psychiatric nurse practitioners. These gaps in training have created what I call a lost generation of clinicians who are hesitant to use clozapine.



**Erik Messamore** is a psychiatrist and associate professor of psychiatry at Northeast Ohio Medical University. He serves as the medical director of the University's Best Practices in Schizophrenia Treatment (BeST) Center. He holds both an MD and a PhD in pharmacology. Dr. Messamore serves on the CURESZ Clozapine in Schizophrenia Experts Panel (CLOSZE).





**visit us at [CureSZ.org](http://CureSZ.org)**

## **YOU** could be one of our featured **SCHIZOPHRENIA SURVIVORS**

The CURESZ Foundation is seeking remarkable individuals to be featured on our website as *"Schizophrenia Survivors."* Despite being diagnosed with this illness, Schizophrenia Survivors are thriving. We work, volunteer and pursue hobbies, and we enjoy meaningful relationships. We have reclaimed our lives and moved beyond the assumed limitations of our diagnosis. Survivors' stories offer inspiration.

Throughout the years, many people have told me my recovery from schizophrenia is the exception to the rule, but I know for certain that is not true. I have come to know too many people who have recovered. We cannot all be exceptions to the rule.

Like me, two of the Survivors completed bachelor's degrees during their recovery, in sociology and engineering. One remarkable woman went on to

graduate with a master's degree in psychology. Another woman thrives in her work teaching others with severe mental illness to share their stories. Eight exceptional individuals are currently featured on CURESZ.org.

In the future, I hope that individuals featured as *"Schizophrenia Survivors"* will come together to meet at a central location for a small conference. We would eventually like to create a book comprised of essays written by people who have *"survived"* schizophrenia.

If you have reached a level of stable recovery from schizophrenia and are interested in being featured on CURESZ.org as a Schizophrenia Survivor, please contact me, Bethany Yeiser at [CureSZ.org](http://CureSZ.org). The CURESZ Foundation reserves the right to full discretion on what is published on our website.

### **VIDEO HIGHLIGHT** **Delusions**

Part Three of Seven  
Bethany discusses her former delusions and their impact on her life and family, together with Dr. Robert McCullumsmith



**[CLICK HERE TO VIEW VIDEO](#)**

### **Please consider sending a donation to the CureSZ Foundation using the enclosed card.**

Your contribution will help provide education and referrals to patients and their families, those who work with the seriously mentally ill. CURESZ informs the general public to better understand this serious brain illness, and to provide scientific advances showing that there is hope for recovery, and a return to a fulfilling and normal life. The CURESZ Foundation is a 501(c)(3) nonprofit organization. All contributions are tax deductible.

***"We are committed to helping patients to cope with and recover from schizophrenia."***