CureSZ
Research | Recovery | Hope

CURESZ FOUNDATION
Newsletter

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Comprehensive **U**nderstanding via **R**esearch and **E**ducation into **S**chi**Z**ophrenia

The Mysterious Disappearance of 2 Million Americans with Schizophrenia

For 3 decades, the academic psychiatric community has agreed that the current U.S. schizophrenia prevalence rate is approximately 1%. Last November, the National Institute of Mental Health (NIMH) unexpectedly revised this figure downward, to 0.3%. Calculating from U.S. census data, 1% of the population translates into 2.8 million people, but 0.3% represents only 750,000 people. The difference between these two numbers is not trivial, because it represents >2 million people. Dr. E. Fuller Torrey, a nationally renowned psychiatrist and researcher, advocate and watchdog of psychiatric care systems and public policy, recently sounded an alarm that NIMH's recent schizophrenia prevalence revision has *"made two million individuals with schizophrenia disappear."*[1] What he meant was not that these people actually disappeared, just that their diagnoses vanished.

How could this happen, and what does it mean? Answers to these questions can be found in history. In the early 1980s, the NIMH-funded Epidemiologic Catchment Area (ECA) study of U.S. psychiatric disorders used rigorous methods and is still considered the most accurate study. Sampling >3,000 adults from households and 500 from institutions (mental hospitals, prisons, nursing homes) in 5 representative sites and administering in-person structured diagnostic interviews, this study reported a 1.1% schizophrenia prevalence. In 2001-2003, the National Comorbidity Study (NCS) was conducted with 9,000 adults randomly sampled only from households (not institutions) selected 73 individuals (from telephone interviews using symptom screeners) to receive diagnostic assessment, from which the prevalence data were derived. This study reported a much lower 0.5% schizophrenia prevalence.

Carol S. North, *MD, MPE*

Such discrepant prevalence rates have been attributed to major differences in research methods and changing diagnostic criteria for schizophrenia. In revising the numbers, NIMH apparently used the NCS results along with many other studies conducted all over the world from various eras that may not apply to current U.S. diagnostic standards, stating: *"the 1.1% figure is no longer scientifically defensible."*[2] Dr. Torrey called this conclusion *"scientifically irresponsible"* and *"egregiously inconsistent with the majority of other prevalence estimates, even with the federal government."*[1]

Why are these numbers so important? Accurate schizophrenia prevalence statistics have far-reaching implications. Allocation of treatment resources depends on accurate numbers of cases. Research funding into the causes of a disorder and to develop effective medications and treatments follows from the perceived magnitude and importance of the disorder. Dr. Torrey criticized the NIMH for neglecting *"our most serious mental illness,"* and he and others[1,3] have urged NIMH to conduct new studies of schizophrenia prevalence. NIMH has indicated that it is in the process of revising its figures.[2] Perhaps they will find the missing cases, as 2 million people is an unprecedented loss of humanity.

References: 1. Torrey EF, Sinclair E. Hocus pocus: how the National Institute of Mental Health made two million people with schizophrenia disappear. *Psychiatric Times* 2018; 35(3):1, 10.
2. Gordon JA. A response from the NIMH director: on the prevalence of schizophrenia and transforming care through research. *Psychiatric Times* 2018; 35(3):11.
3. Pickar D. The prevalence of schizophrenia in the U.S. *Psychiatric Times* 2018; 35(4):5.

WhatSZ IN THIS EDITION

Survivor Highlight: Bill MacPhee — Pg 2
CureSZ Brain Facts — Pg 2
An Interview with Dr. Erik Messamore, MD, PhD — Pg 3
Tardive Dyskinesia — Pg 4
Video Highlight: What are the Risk Factors and Treatments for TD? — Pg 4

CureSZ News

SCHIZOPHRENIA SURVIVORS

The Story of Bill MacPhee

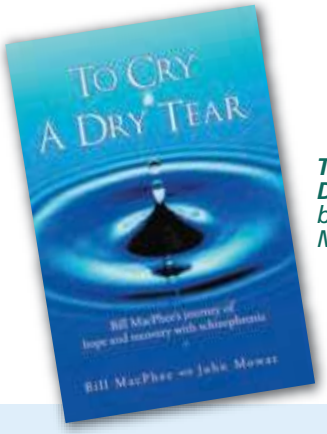
Bill MacPhee's life dramatically changed at age 22. Amidst great conflict and confusion he recalls *"looking for something,"* and seeking to discover his own personal niche. To this end he began spending an excessive amount of time each day in religious studies. Eventually, even friends with similar interests began to voice concern that something was seriously wrong with Bill.

One day, convinced that he needed to circle *"Jericho"* like the Biblical Israelites, Bill drove a thirty kilometer stretch of Toronto highway seven times. This delusion was just the beginning of his journey into severe psychosis. As weeks passed, he came to believe he was part of a divine mission.

In February of 1987, at age 24, Bill experienced his first psychotic break and was committed to a hospital. He was prescribed medication which significantly relieved his symptoms and eventually brought him into remission.

In June of 1987, feeling confident he was *"cured,"* he worked with a physician to discontinue his medications. For six weeks he remained stable under the doctor's supervision, but without medication he again experienced a psychotic episode. In December 1987 he was re-hospitalized and then discharged in January 1988.

Fortunately, during this final hospitalization, a new medication was prescribed which provided him full relief from hallucinations and delusions. This year, 2018, Bill celebrates a twenty year anniversary of full recovery from schizophrenia and his retirement from employment as a mental health advocate.



To Cry A Dry Tear, *by Bill MacPhee*

When looking back on his 55 years of life and two decades of recovery from schizophrenia, Bill listed the most important things he has learned:

Lesson 1: Develop a social network. Work on finding good friends, and discover how to become a good friend. Expand your social life to include people of all walks of life -- don't lock your sights exclusively on people who have mental illness.

Lesson 2: Take your medication and learn to understand your diagnosis. Bill has been on an injectable medication for most of his 31 years dealing with a mental illness. You cannot have a good quality of life if you are hearing voices, if you are paranoid, if you are delusional, or if you can't get out of bed.

Lesson 3: Find something to occupy your time. Having nothing to do is worse than having too much to do. We need to find purpose in things we like or want to do.

Lesson 4: Don't be too proud to ask for help when you need it. You are actually blessing people when you seek their help.

Lesson 5: Keeping life simple is fundamental. Try to be a thankful and joyful person and live one day at a time.

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Brain Facts

by Henry A. Nasrallah, MD
CURESZ Scientific Director

- The human brain is 2% of body weight but consumes 20% of the energy produced by the mitochondria.
- It is comprised of ~100 billion neurons and glia, plus trillions of synapses.
- The brain is 40% gray matter and 60% white matter.
- It has 137,000 miles of myelinated fibers to connect all the brain regions together.
- During fetal life, the brain grows by 250,000 neurons EVERY MINUTE!
- The brain continuously changes with every experience, creating dendritic spines to encode new learning. No other organ in the body changes its structure every day!
- The brain has 2 neurogenic regions (i.e. factories) that make new baby neurons and glia every day throughout life. Psychosis, drug abuse or severe medical illness may cause the newborn neurons to die instead of maturing.
- The brain is 75% water, so even 2% dehydration can affect memory and attention!
- Running a marathon without adequate hydration shrinks the brain equal to 1 year of aging.
- Self-awareness , also called *"meta-cognition" is* believed to be located in the prefrontal cortex.

EXPERT
INTERVIEWS

An Interview with
Dr. Erik Messamore, MD, PhD
Part 3 of 4

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).

Q What do you think makes clozapine effective in situations where other medications have not been?

Not all schizophrenias are alike. Understanding that there are different kinds of schizophrenia helps to explain why clozapine appears uniquely effective.

Most schizophrenias should probably be renamed "*dopamine psychosis.*" Scientists have shown that many people with schizophrenia have unusually high dopamine signals in key brain circuits. These findings explain why antipsychotic medications are effective. Most all of them are designed to adjust the elevated dopamine signals. About two thirds of people with schizophrenia will have one of these high-dopamine forms of illness and will find relief from dopamine-adjusting medications.

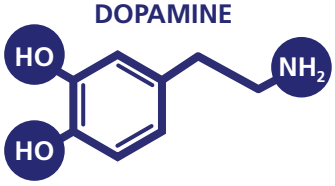
But there are other forms of schizophrenia where the dopamine signal appears entirely normal. A variety of neurochemical studies, including some recent PET scan work, has shown that people with these normal-dopamine schizophrenias don't get much symptom relief from the first-line, dopamine-adjusting schizophrenia medications. This makes sense. Why would we expect that dopamine-focused medications would benefit someone without a high-dopamine brain?

"*Treatment-resistant schizophrenia*" is the name that the field has sort of settled on to refer to the forms of schizophrenia that don't respond to non-clozapine medications. This label is unfortunate, in my opinion, because it is both discouraging and misleading. The majority of so-called treatment-resistant cases actually respond beautifully to clozapine. It's not that these illnesses were resistant to treatment. It's that these folks have a normal-dopamine form of schizophrenia that won't be served by dopamine-adjusting meds. Clozapine works in the majority of these schizophrenias because clozapine is not a dopamine-adjusting medication. Clozapine is the only thing we know of that works well for normal-dopamine schizophrenia.

Q How does someone know if they have a high-dopamine or a normal-dopamine form of schizophrenia?

It's possible to measure dopamine signaling in humans, but the techniques are not available outside of research studies. On the other hand, medication response patterns can be useful guides. If symptoms respond to dopamine signal adjusting medications, its quite likely that the psychosis was of the high-dopamine type. On the other hand, if symptoms have not much improved despite adequately-dosed dopamine signal-adjusting medications, then a normal-dopamine psychosis is likely. Paying attention to medication response is an indirect method of finding out if someone has a high-dopamine schizophrenia or a normal-dopamine schizophrenia.

DOPAMINE



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TARDIVE DYSKINESIA

Tardive Dyskinesia is always a potential neurological adverse effect of dopamine receptor blocking agents, which includes all antipsychotic medications. It presents as involuntary movements often seen in the face, including the tongue lips, jaw and eyes but can also affect the neck, arms, fingers, legs, trunk or diaphragm. The abnormal movements can be disfiguring and embarrassing to patients.

TD is different from the acute abnormal muscle movements or rigidity called Extra Pyramidal Side Effects, or EPS, which usually resembles symptoms of Parkinson's Disease but often includes other symptoms such as restlessness (referred to as akathisia) and dystonia.

TD often appears after months but more usually years of antipsychotic therapy. There are several risk factors for TD including high dose and long duration of antipsychotic treatment, older age, female gender, diagnosis of a mood disorder, drugs and alcohol use, and diabetes. It is estimated that 500,000 persons in the U.S. currently suffer from TD.

Fortunately, effective treatment for TD is available today. Valbenazine was approved by the FDA in April 2017, and deutetrabenazine was subsequently approved in August 2017. These medications have to be taken permanently because if stopped, the involuntary movements of TD will return. These medications are highly effective and can significantly improve the quality of life of individuals afflicted by TD.

VIDEO HIGHLIGHT

What are the Risk Factors and Treatments for TD?

Part Three of Four

Dr. Henry Nasrallah and Bethany Yeiser discuss tardive dyskinesia.

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."