Message from SARDA, CEO

Dear friend,

In Memory of Dr. Frederick Frese
July 16, 2018 Brain Health Advocate Extraordinaire
died
SARDA mourns the loss of the unequivocal Hero and Icon of hope, resilience, education, courage and advocacy for all affected by psychosis and other psychiatric illnesses.
Dr. Frese, lovingly referred to as “Fred”, profoundly changed the understanding of what psychosis is and the challenges faced by all affected. He was the most articulate and entertaining speaker I have ever had the honor of hearing. He could present the most serious of information in a belly-laugh worthy fashion.

Fred will be remembered for his kind, open, genuine, generous, brilliant friend to all that he was. Fred fearlessly initiated the open and profoundly revealing public discussions and presentations about serious psychiatric illnesses. He spoke of his experiences with psychosis, treatment and the multiple challenges that he and the millions of others who live with schizophrenia face.

He has changed the world and we are the beneficiaries who must continue his passionate crusade to change how people are treated both medically and socially.

Among many other very powerful and prestigious positions, Dr. Frese was a member of the SARDAA founding steering committee and influenced many formational decisions. Fred was the recipient of numerous awards and honors including SARDAA’s highest honor the “Shattering Stigma – Realizing Recovery” Award and the SARDAA nominated NCBH Advocacy Award. Fred and his amazing wife Penny spoke at several of our conferences and were always the highlight of our events. One year our conference was based on the video “Minds On The Edge” where he was a panel member playing the role of someone with schizophrenia who didn’t believe they were ill and needed help and then sat on our own panel to answer questions. When SARDAA exhibited at National NAMI conferences, Fred would come sit at our booth and be a delightful representative of the heart and soul of SARDAA.

Our prayers and heartfelt caring thoughts are extended to Penny, their children, grandchildren and their entire family. SARDAA and the world mourn with you.

Thank you, Dear Fred, for all you have given to the world.

Warmest regards,
Linda Stalters, MSN, APRN (ret)
Chief Executive Officer
Schizophrenia And Related Disorders Alliance of America

Pete Earley presents a beautiful story of our dear friend, colleague, activist and pioneer. READ HERE
The Friend and Family, FFS phone support group is on Tuesdays at 7 pm ET. Given the time zone difference of three hours between East and West coasts it is challenging to meet everyone's needs, so we would like to establishing a second group for the west coast callers. If you, or anyone you know, would be so committed to starting such a group please contact CEO Linda Stalters at linda.stalters@sardaa.org.....much gratitude.

Yellow sun shines brightly
Flowers and lawn is sightly
Furballs come in nightly
The yellow house goes on

The stars glimmer through the city lights
Temperature stays cool through the summer night
The yellow house goes on

The yellow house has been through much
Hurricanes/flooding and now this
I know the yellow house will go on

I love you

-Dylan

Sanity is a matter of perspective and perspectives change
I believe you are insane
Primarily due to what you say
But Perhaps you are of sanity
An ideal which is unknown to me
A predicament which could hardly be helped
When one considers the environment of self

By Keith Coltrane

Personal Story of SA Members

Bill S.
I was diagnosed with chronic undifferentiated schizophrenia in 1969 when I was 21, or rather misdiagnosed. The psychiatrist I saw was Hungarian and he didn’t understand my English that well. I was prescribed old line anti psychotics for what was essentially an anxiety reaction. They just intensified the anxiety reaction. It was only later that I developed a psychosis.

At first I did not take my medications regularly, so I was in and out of the local mental health hospital during my twenties. It took some time before I figured out that I needed to take the meds to stay out of the hospital and in the real world. I was very shy and insecure. Fortunately, my parents stuck with me through this time. I don’t know what I would have done without them.

I went from job to job. I couldn’t keep a job for more than a few months. I could do the work, but I had trouble with my supervisors. I thought they were abusive. Eventually, I went back to school. I got two bachelors’ degrees, both with good grades, one in history, one in elementary education. Again, I could not keep a job. Finally, I figured out I needed to stay on my meds. When I did, I work for almost ten years straight. After three and a half years of working a delivery job I got a job as a letter carrier for the U. S. Postal Service. I did that for six years. It was ok, but I wanted more from a job. I applied for and was admitted to a local law school. I reduced my medication level so I could study better. It was a mistake. I had a relapse. I ended up on a road trip to California. It was a great experience, but I needed to come back to the real world.

To make a long story short, I got back on my meds and got a job in peer support. My first job was as a facilitator for a Schizophrenia Alliance group in a local hospital. I worked for a peer-run mental health organization in Southern California. It was the job I was looking for. It had a human element to it. We had a great peer support program. I was promoted to full-time. I did the SA group for several more years, then I hired other participants to facilitate the group. I thought I had it made. I worked for eight years. I started to lose weight so I reduced my meds accordingly with my doctor’s help. It didn’t work out. I had another relapse. I lost my job. I gained back all the weight I had
lost. I ended up in Oklahoma in a nursing home wondering what I would do. I wondered if I would ever work again.

I got out of the nursing home and started to lose weight again. Fortunately, I was able to get another job in peer support in Oklahoma City. I remembered my experience with SA. I believe in the SA program. I was sure to include the group in our curriculum. This time I plan to stay on an adequate level of medication. I have been working for over a year and a half. I am starting to get my life back together.

I have learned never to give up hope. There is a light at the end of the tunnel.

We welcome your message/art from SA Members for inclusion in the newsletter. Please submit your message to: info@sardaa.org or mail to SARDAA PO Box 941222, Houston, TX 77094-8222 for consideration for next month's newsletter.

Your story might be included in a SARDAA newsletter and might be published in a future edition of the SA Blue Book.
Phone Support Groups

SA Conference Call Groups
Only for individuals diagnosed
Sundays - 7 pm Eastern Time
Mondays - 4 pm Eastern Time
Thursdays - 7 pm Eastern Time
Fridays - 7 pm Eastern Time
Saturdays - 1 pm Eastern Time

Students or Early Intervention of Psychosis SA Conference Call Group
Second Wednesday of each month - 7 PM Eastern Time

Spirit of SA Conference Call
For SA Leaders and Potential Leaders
First Wednesday of Each Month - 7 pm Eastern Time

Family and Friends Support Group
Not for individuals diagnosed
Every Tuesday - 7 pm Eastern Time
Toll-free Calls
Call-in information (855) 640-8271
Entry Code 88286491#
International Number (720) 362-6499

Facebook Support Group
Only for individuals diagnosed
JOIN The Facebook Group Here
This is a Closed group, ask to be added.

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Psychosis: Does Language Make a Difference?
Linda Stalters, MSN, APRN(ret), SARDAA CEO
Currently, there seems to be an over sensitivity to language. However, when
we are considering the seriousness of how language affects the most
discriminated against, severely abused, victimized, misunderstood, ostracized
and untreated individuals and their families, it DOES make a difference.
According to the Webster’s Dictionary the word schizophrenia combines the
Greek skhizein "split" and phren "mind." Thus, the misleading perception that
the illness is "split personality" or “multiple personalities”. Schizophrenia is
nothing of the sort. It is a neuro-circuitry brain illness that requires medical
treatment as does diabetes or cardiac disease.

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Schizophrenia Should be Classified as a Neurological Brain Disease
Linda Stalters, MSN, APRN(ret), SARDAA CEO
The Schizophrenia And Related Disorders Alliance of America vision is every
person living with a schizophrenia-related brain illness receives respect,
appropriate treatment and an opportunity to live a meaningful life in a
compassionate community free of discrimination.

There is scientific consensus that schizophrenia is a brain-based, highly
heritable, neurodevelopmental disorder, with disease processes commencing
early in neurodevelopment. Synaptic pruning – that refines neural circuits
during neurodevelopment – is perturbed, in particular during adolescence,
consistent with the typical onset of illness during this period and into young
adulthood.

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Should Schizophrenia Be Re-classified?
Linda Stalters, MSN, APRN (ret), SARDAA CEO
A comparison of schizophrenia to Alzheimer’s disease and Parkinson’s
disease – two disorders that unambiguously have a neurological basis –
quickly makes a compelling case for schizophrenia finding its proper diagnostic
home in the neurological disorders (see Table below). All three disorders share
multiple features including significant brain and cognitive deterioration,
diagnostic approach, types of treatment, having a strong genetic basis, clearly
speaking to the consideration of schizophrenia as a neurological disorder (interestingly, schizophrenia appears more heritable than Parkinson's disease).

Addressing the Challenges of the Opioid Crisis and Serious Mental Illness
SAMHSA
SAMHSA's Efforts are Aligned with the HHS Five-Point Opioid Strategy. Strengthening public health surveillance, advancing the practice of pain management, improving access to prevention treatment and recovery support services, targeting availability and distribution of overdose-reversing drugs and supporting cutting-edge research.

Study Casts Doubt on Effectiveness of e-cigs for Smoking Cessation
NIH
July 9, 2018
A study found no evidence that smokers who used e-cigarettes and other electronic nicotine delivery systems (ENDS) in the United States were more likely to quit smoking cigarettes than smokers who do not use these products. The study, looking at 2015-2016 data, found that 90 percent of people who used both ENDS and traditional cigarettes (dual users) were still smoking one year later. The research was conducted by researchers at the School of Public Health at Georgia State University and funded by the National Institute on Drug Abuse (NIDA), part of the National Institutes of Health, and the U.S. Food and Drug Administration, Center for Tobacco Products.

Why do we so consistently underplay the links between cannabis and psychosis? This isn’t a benevolent drug
Patrick Cockburn
June 22, 2018
Anybody wondering what happens to the 8 per cent of the skunk-smoking population who develop mental illness should visit any psychiatric hospital in Britain or speak to somebody who has done so.

What is really needed in dealing with cannabis is a “tobacco moment”, as with cigarettes 50 years ago, when a majority of people became convinced that smoking might give them cancer and kill them. Since then the number of cigarette smokers in Britain has fallen by two-thirds. A depressing aspect of the present debate about cannabis is that so many proponents of legalisation or decriminalisation have clearly not taken on board that the causal link between cannabis and psychosis has been scientifically proven over the past ten years, just as the connection between cancer and cigarettes was proved in the late 1940s and 1950s.

Co-occurrence of Physical Health Conditions and Mental Health and Substance Use Conditions
Agency for Healthcare Research and Quality
HCUP Statistical Brief 240
June 2018
Co-occurrence of Physical Health Conditions and Mental Health and Substance Use Conditions Among Adult Inpatient Stays, a statistical brief from the Healthcare Cost and Utilization Project, presents data on the co-occurrence of physical health conditions and mental and/or substance use disorders (M/SUDs) among adult inpatient stays in 2010 and 2014. Comparisons in the 2 years are made for the prevalence of stays for M/SUDs (i.e., principal diagnosis) with a co-occurring physical health condition (i.e., secondary diagnosis) and for the prevalence of stays for physical health conditions (i.e., principal diagnosis) with a co-occurring M/SUD (i.e., secondary diagnosis).

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FDA Approves First Drug Derived from Marijuana
NIH
July 2, 2018
Last week, the Food and Drug Administration (FDA) approved Epidiolex (cannabidiol, or CBD), a medication extracted from marijuana, for the treatment of two severe pediatric seizure disorders, Lennox-Gastaut syndrome and Dravet syndrome. CBD is a compound typically found in very small quantities in the marijuana plant, and it has been of interest to scientists and the public for several years due to its anti-seizure properties and other possible therapeutic benefits. The approval comes at the end of a four-year series of trials showing the benefits of CBD in relieving the symptoms of these seizure disorders, which are highly resistant to existing treatments.

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Gene Variation Accounts for Why Antipsychotics Reduce Cognitive Symptoms in Some Patients
Brain & Behavior Research Foundation
Antipsychotic medications are a cornerstone of treatment for schizophrenia and related disorders. They prevent hallucinations and delusions for most people, and for some, they also help reduce the cognitive impairments associated with these illnesses, such as problems with memory and attention.

Now, researchers have identified a genetic factor that determines which patients are likely to experience cognitive benefits from antipsychotic medications.

The cognitive symptoms of schizophrenia are often the symptoms most debilitating and difficult to treat, and clinicians have lacked tools to help determine the best approach for managing these symptoms in individual patients. The new finding could enable a more personalized treatment approach.

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Letters: Jails Can't be Mental Health Centers
Janet Hays
July 11, 2018
Gerald Davis, 25, said he spent eight months pre-trial waiting in jail during a rally to announce public records requests by Operation Restoration, Voices of the Experienced (VOTE), and the American Civil Liberties Union of Louisiana,
in order to find out the number of people being held in Louisiana jails awaiting trial in New Orleans, La. Monday, April 30, 2018. Next Davis is Austin Badon, former state representative to Orleans Parish, New Orleans City Council At-Large Division 2 Jason Williams, second left, and Norris Henderson, with Voice of the Experienced.

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Nation's largest Suicide Prevention Organization Thanks Members of Congress for Passing the National Suicide Hotline improvement Act (H.R. 2345 & S. 1015)
American Foundation for Suicide Prevention
July 23, 2018
Today the U.S. House of Representatives voted to pass the National Suicide Hotline Improvement Act. The Senate unanimously passed the same bill in October 2017. John Madigan, the senior vice president for public policy fro American Foundation for Suicide Prevention (AFSP), the nation's largest suicide prevention organization, released this statement:

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National Minority Mental Health Awareness Month
July 2018
July is National Minority Mental Health Awareness Month and the month offers organizations of all types and sizes an opportunity to create mental health awareness in diverse communities. The U.S. House of Representatives proclaimed July as this special month in 2008, aiming to improve access to mental health treatment and services through increased public awareness. Since then, many organizations have hosted a variety of events and activities in communities across the country each year.

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Highlighting Services and Effectiveness Research at NIMH
Joshua Gordon
June 26, 2018
NIMH envisions a world in which mental illnesses are prevented and cured. Our vision statement says it all. We won’t stop our efforts to transform the understanding and treatment of mental illnesses until that vision is realized. To that end, we invest in basic research to understand the mechanisms and origins of mental illnesses, as well as translational research to develop novel treatments and prevention measures based on this understanding. But research doesn’t stop with the discovery of a new treatment. In order to prevent and cure illnesses, these treatments need to actually be tested and put to use in the clinic. Once the effectiveness of an intervention is established, figuring out how best to deliver effective therapies is the domain of services research, a key component of our research portfolio at NIMH that focuses on impacting patients in the near term.

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Inflammation in Pregnant Moms Linked to Child's Brain Development
NIMH
July 24, 2018
Effects on connectivity, wiring, memory, impulse control may predispose for disorders. NIMH-funded researchers are connecting the dots between inflammation in a pregnant human mother and possible effects on her young child’s developing brain. So far, they have linked high levels of maternal inflammation during pregnancy to reduced brain circuit communications and altered long-distance brain wiring at birth, poorer cognitive function at one year – and to reduced impulse control and working memory at two years.

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**Predicting Suicide Attempts and Suicide Deaths Using Electronic Health Records**
NIMH
July 12, 2018
New model substantially outperforms existing suicide risk tools. Suicide accounted for nearly 45,000 deaths in the United States in 2016. Unfortunately, tools currently used to predict an individual’s risk of a suicide attempt or dying by suicide, such as brief self-report measures, have only moderate accuracy. Now, researchers have developed a new prediction model that substantially outperforms existing self-report tools. The study, supported by the National Institute of Mental Health (NIMH), was published online on May 24, 2018, in the American Journal of Psychiatry.

**READ MORE**

**Understanding Critical Components of the Brain's Stress Circuitry**
NIMH
July 9, 2018
Study identifies how the PVT interacts with other brain areas during stress. Everyone feels stressed from time to time. While people often learn to deal with stress in a healthy, adaptive way, sometimes people respond to stress in a maladaptive way, which can put them at greater risk for developing mental illnesses. Now, a new study conducted by researchers at the National Institute of Mental Health (NIMH) has revealed more about the organization and function of a brain structure that may serve a key role in linking stress detection to the development of adaptive behaviors. The study, published online June 18, 2018, appears in Nature Neuroscience.

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**Comments Sought for AHRQ Effective Health Care Program Report**
The AHRQ’s Effective Health Care Program encourages the public to participate in the development of its research projects. The Program uses these comments to help focus its research and ensure that the final comparative effectiveness reviews answer the most important questions that clinicians, patients, consumers, and policymakers have about a given treatment, test, or procedure. The Program is currently seeking comments for: **Key Questions: Mental Health Treatments in Pregnancy** (Comments accepted through July 30, 2018)

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**WEBINAR: Using Simulation to Evaluate Social Determinants of Health in People with Mental Illness: Potential Use of Findings in Discussions with Policymakers, Community Groups, Consumers and Advocates**

**READ MORE**
August 6, 2018, 4:00-5:30 PM ET
Improving the efficacy of treatment among socioeconomically diverse populations with mental illness requires tackling the myriad of social determinants of health, including education, income, and employment. Modern research techniques, like simulation testing, can lead to efficient and effective intervention design among people with mental illness by giving an indication of what might work. This webinar in the 2018 NIMH Office for Research on Disparities and Global Mental Health Webinar Series will cover evidence for addressing social determinants; the use of simulations to test the potential of improving income, education, and employment to improve mental health outcomes using two data sets; illustrate the reactions from policymakers, community groups, consumers and advocates on the research results; and demonstrate how research results can inform policy.

INFORMATION and REGISTRATION

WEBINAR: Using Simulation to Evaluate Social Determinants of Health In People With Mental Illness: Potential Use of Findings in Discussions with Policymakers, Community Groups, Consumers, and Advocates
September 11, 2018, 4:00-5:30 PM ET
Improving the efficacy of treatment among socioeconomically diverse populations with mental illness requires tackling the myriad of social determinants of health, including education, income, and employment. Modern research techniques, like simulation testing, can lead to efficient and effective intervention design among people with mental illness by giving an indication of what might work. This webinar in the 2018 NIMH Office for Research on Disparities and Global Mental Health Webinar Series will cover evidence for addressing social determinants; the use of simulations to test the potential of improving income, education, and employment to improve mental health outcomes using two data sets; illustrate the reactions from policymakers, community groups, consumers and advocates on the research results; and demonstrate how research results can inform policy.

INFORMATION and REGISTRATION

Find Clinical Trials by State: CLICK HERE
Nationwide Recruitment: NIMH Study

Donate to SARDAA
Brain Campaign:

Take the Pledge

I will change my language from Behavioral or Mental disorder to Brain disease.
I will educate others to change their language from mental illnesses to brain illness.
I will not use stigmatizing, discriminatory or derogatory language related to brain diseases.
I will encourage my peers, family members, and colleagues to advocate when they see discriminatory language or practices in the media or in public.
I will advocate that people with brain diseases have equal and comprehensive health care.
I will treat all people with brain diseases with respect and compassion.

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Amazon donates to Schizophrenia & Related Disorders Alliance. Shop for great deals at smile.amazon.com/ch/33-1213657
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Search for and select Schizophrenia and Related Disorders Alliance of America as your charity. Once selected, you will receive a confirmation email.

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Please share with your friends and family to join you to support Schizophrenia and Related Disorders Alliance of America!

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Please take a moment to find out how you can help support SARDAA, not only today but every day - **at no extra cost to you!!**

**IT'S SO SIMPLE: just bookmark this link** http://smile.amazon.com/ch/33-1213657, **start shopping and support us every time you shop.**

Shop with **PayPal** and choose **SARDAA** to Donate with PayPal Giving Fund to help support SARDAA.

**Texas and Louisiana Friends:**
**Re-Enroll Your Kroger Plus Cards**

You can support SARDAA without spending a penny! Register Schizophrenia and Related Disorders on your Kroger Plus Card and they will donate a percentage to SARDAA each time you use your card.

Please register online at [www.krogercommunityrewards.com](http://www.krogercommunityrewards.com)

Link to: Schizophrenia and Related Disorders–Kroger Plus Card 90425
Help Change Lives -- Donate Now

Thank you to those who already made a donation.
Every contribution makes a difference.

Sincerely,
Jordan Helwig, Creative Designer
Angel White, Editor