Message from SARDAA, CEO

Dear Friends,

April is the time the beauty of Spring emerges, albeit, locations continue to enjoy the lovely snowfall. April is also time to prepare an activity to inspire and create awareness around Schizophrenia Awareness Week (SAW) the 3rd week of May, and Schizophrenia Awareness Day May 24th. Talk with your local policy makers and implore them to consider their most needy and sometimes their most helpless constituents - individuals who live with untreated schizophrenia brain illnesses. Help your community know that jails & prisons are not treatment facilities and treatment, housing and compassionate care is necessary just as it is for heart, kidney or any other disease.
Form an activity that helps people understand the plight of people who are affected by schizophrenia and do not receive care.

We continue to work with other organizations to collaborate on efforts to reclassify schizophrenia spectrum brain illnesses. Dr. William Lawson organized the opportunity for us to speak about reclassification at the Black Psychiatrists of America Conference in DC. The attendees welcomed the initiative and highly respect Dr. Lawson and his presence.

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

Delightful dinner with Dr. E. Fuller Torrey, his wonderful wife Barbara, SARDAA board chair, Dr. Raymond Cho, SARDAA board member Dr. Robert Laitman and SARDAA CEO Linda Stalters. Dr. Torrey shared his wisdom, humor and his seventh edition of Surviving Schizophrenia.
SAVE THE DATE!

NOVEMBER 4, 2019
The Westin New York at Times Square

Brains on Broadway
Symposium & Educational Awards Reception

Symposium
Translation to Transformation
2:30pm-5:30 pm

Star Studded Reception
Brains on Broadway
6:30pm-8:30pm

WWW.SARDAAN.ORG  (240) 423-9432

Purchase Your Brains on Broadway Tickets **Now**!
Limited Space Available
Early Registration Discount with code: EARLY

Nominations for SARDAA Annual AWARDS

Dr. Frederick Frese Award
Joanne Verbanic Award
Valiant Researcher
Exceptional Media Award
Clinician Extraordinaire Award

Please submit your nomination no later than
(extended) **MAY 15, 2019**

**Award Criteria and Form**

Message from FFC, Families for Care, Coordinator
Compassion...“a capacity for sharing painful feelings of another accompanied by a feeling to aid or spare”, “understanding of
another's pain and a desire to somehow mitigate that pain”, according to Merriam-Webster. On my path as a care partner, I am familiar with this emotion, thus in my search for understanding I happened onto a website, and global movement, called ‘Compassion It'. This movement was founded by a woman named Sara Schairer, who through her own struggles and challenges, sought to bring awareness to the positive possibilities inherent in a world in which compassion is highly valued.

The site is www.compassion.com if you’ve time and interest to know more. It leaves me believing it would be a better world for 'people challenged with SMI and their support persons', for 'persons with disabilities of any and all kinds', for 'differences in this world of whatever'.....wouldn't it be a kinder and more accepting place if more people were to 'compassion it'? As I’ve referred to meditation in a previous message, becoming more compassionate is a benefit, or gift, gained through the practice, beyond stress reduction and relaxation.

With Heart,
Mary Ross

---

**Message from SA Staff Supporter**
Starting SA Meetings – How Do You Plan The Structure Of The Meetings?
By Sandy Dimiterchik

A while ago, I heard from our Hungarian Group, SA Hungary Siófok, about planning the structure of the meetings. They had an innovative way for people to share what is going on in their life and wanted to make sure it was okay. I was excited to hear about the planned structure of the meetings.

For people interested in starting SA groups, you can find a section in the 2018 Blue Book, called “Structure of Meetings” on page 10. According to the Blue Book, “SA meeting formats vary according to members’ preferences and the leader’s style. (Page 10)” There is more information in the “Elements of a Regular Meeting” section on Pages 10 – 11 and an actual format in the section “SA Psychosis Support and Acceptance Sample Meeting Format” on Pages 13 -15. If you have questions, you can always contact the SA Staff Supporter, Sandy Dimiterchik, at 832-439-1586 or sandy.dimiterchik@sardaa.org.
For people interested in starting a group or even participating in a group, I recommend they participate in a conference call. First, they need to register by calling the office at 1-240-423-9432 or 1-800-493-2094. Through the office, get the toll-free number and passcode (or international number as we have group members in other countries who like to call in), Then, call in, announcing who you are. The conference calls are led typically by two facilitators and last an hour to an hour and a half depending on the day. For more information, go to our website, SARDAA.org. In the US, you can find in-person groups on our Group Locator on our website. For people in other countries, groups are also held in Hungary, Russia, Iran, Kenya, India, and Orebro.

**WE want to hear from you!** SARDAA is in the process of evaluating the effectiveness of the SA groups. These groups are held in-person and by conference calls. The in-person groups can be found throughout the United States and internationally. It is critical to know the benefits of the support groups as there are also other support groups out there, and we at SARDAA want to make sure we are serving a purpose. Please complete the questionnaire [HERE](#).

**Personal Story of SA Members**

**Laura**

My name is Laura. I am a paranoid schizophrenic working for recovery. Prior to starting the SA group, I had lost my job and had no social life. Within four months, I had enough confidence in myself to begin again. So, I enrolled in college and became a leader of a chapter of SA. The first semester I had to withdraw due to my illness, but with the help of the group and my therapy, I managed to stay out of the hospital. I didn’t give up. I went for the winter term and reduced my classes. To my amazement, I did quite well. I have a 3.6 average, and I will be returning this fall.

Needless to say, I have made many friends. With the help of everyone around me, I can go forward with being both happy and successful. Realizing that I do have limitations was very hard. But it is the key that is opening doors to success for me.

---

**Are you or someone you know a Social Media expert? SARDAA needs volunteers!**

Please contact: Angel 240-423-9432 or angel.white@sardaa.org

[View Requirements HERE](#)
This book is a good example of the difficulties of treating brain disorders for people who are in college. I found the book easy to read and finished it quickly. I recommend the book for the diagnosed, family and friends, and SA groups. It is very descriptive and really portrays what goes on when a person is manic or psychotic. The book is also inspirational, as the main character is able to pursue his dreams, even though they are not what he first originally planned. He is very brave to share his story, so that other students will see that they can also graduate, even get a Ph.D., and work as a professor.

Even though this happened 10 years ago, I think that there is still a lack of knowledge at universities of how to manage students with brain disorder disabilities. There is not enough insight and there is stigma as staff and faculty do not know how to handle somebody having mania and/or psychosis. Too many times the students end up arrested or hospitalized since the symptoms can be scary and threatening.

The positive side to a story like this is that there are now facilities to help young adults pursue goals. Now throughout the US there are early psychosis treatment centers which help students with their scholarly goals and/or vocational plans. Organizations such as SARDAA educate and provide support to the diagnosed, family and friends by referring them to resources. Also, I recommend students contact A.D.A. (Americans with Disabilities Act) offices to find out what help they can get due to their disabilities.

People can purchase the physical book soft and hardcover through amazon.com, or order through Barnes and Noble at this time. Also, people may go directly to authorhouse.com, which is the publisher; to order the book.

There are a number of e-book vendors out there, including google.com which sell electronic versions of the book.

---

**We are actively recruiting State Chapter Leads, State Chapter Members, and Families for Care Group Leaders**

SARDAA is the only advocacy organization focused on psychosis, the most debilitating symptom of brain illness.
Are you interested in starting a SARDAA State chapter, being a chapter lead, or member? Running a local Families For Care support group? Helping other families in their journey through brain illness? Contact Laura Pogliano, laura.pogliano@sardaa.org or call 240-423-9432.

We will send you all the info you need to get help for your family & find resources on brain illness, and also information on starting a state chapter, becoming a member and forming a local support group.

We need you! Join us in making a difference.

Our mission: improving the lives of people living with psychosis!
Thank you, Laura Pogliano

---

**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

**Spirit of SA Conference Call**

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

**Families For Care Conference Call**

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 Groups
Only for individuals diagnosed
SARDAA Support
JOIN The Facebook Group Here

Only for Caregivers
SARDAA Families for Care
JOIN The Facebook Group Here

Diagnosed, Caregivers, Professionals
LOBBY CCAC - Circle of Comfort and Assistance Community
JOIN The Facebook Group Here
These are Closed groups, ask to be added.

Become a SARDAA Pen Pal

Have you ever wanted to be a pen pal? By pen pal, we at SARDAA mean someone who corresponds with a person who has schizophrenia or related disorders, including bipolar disorder, schizoaffective disorder, depression with psychosis or experience with psychosis. The person you are writing to could possibly in prison, a hospital, or neither, just someone with the diagnosis looking for a friend to correspond with. You can specify. Also, you can be anonymous, receiving an anonymous SARDAA email address or sending your letters anonymously to our office staff, who will then send the letters to the person.

If you are interested, please contact the office at 1-240-423-9432, 1-800-493-2094 or info@sardaa.org
-Sandy Dimiterchik

Black Psychiatrists of America, Inc. 50th Anniversary Conference in Association with The National Medical Association: Black Mental Health: Lessons from the Past, Challenges in the Present and Healing for the Future Panelists pictured: Dr. Cheryl Cottrol, Dr. William Lawson and Linda Stalters, SARDAA.
Personal Story
March 2019
Mary Troy
What happened on Wednesday afternoon/evening on Yakey Lane?
I’ll tell you what happened in hopes of bringing something positive out of this unforgettable traumatic day. I’d like to use it as a “teachable moment” for those who are blissfully unaware of how archaic our current mental health laws are and how we need immediate mental health reform. It’s long so read on if you dare....

READ MORE

NAMI Summit County Annual May Luncheon
Thursday, May 16, 2019, 11:30 am - 1:00 pm EDT
Hilton Akron/Fairlawn, 3180 W. Market St., Akron, OH 44333
Please Join Us on May 16th for our Annual May Luncheon where Dr. Xavier Amador will be our Keynote Speaker. "I AM NOT SICK, I Don't Need Help" Don't miss this opportunity to learn about the LEAP communication technique.

GET more information
Register HERE

A Medicine That Treats Mania Also Shows Effectiveness in Treating Depression in Bipolar Disorder
March 8, 2019
American Journal of Psychiatry
Cariprazine, a medicine approved by the FDA in 2015 for the treatment of manic episodes in bipolar I disorder, was effective in reducing depressive symptoms in bipolar I disorder patients in a phase 3 clinical trial reported March 8, 2019 in the American Journal of Psychiatry.

The medicine, sold under the brand name of Vraylar in the U.S., interacts with specific receptors for dopamine and serotonin in the brain. In the class of “atypical” or second-generation antipsychotic medicines, it has been used primarily to treat people with schizophrenia and bipolar mania.

READ MORE
Helping Someone with Schizophrenia: Overcoming Challenges While Taking Care of Yourself

HelpGuide.org

The love and support of family and friends plays an important role in schizophrenia treatment. If someone close to you has schizophrenia, you can make a huge difference by helping that person find the right treatment and self-help strategies, cope with symptoms, and build a fulfilling life. A diagnosis of schizophrenia is not a life-sentence for your loved one. Recovery is possible, especially with your support. While dealing with a loved one’s schizophrenia can be challenging, these strategies can help you guide your loved one on the road to recovery without losing sight of your own hopes and dreams.

Where Did the Schizophrenics Go?
March 26, 2019
E. Fuller Torrey and Wendy Simmons

The number drops to 750,000 from 2.8 million, and spending per patient soars.

Wondrous are the ways of Washington. In a single day, the federal government officially reduced the number of people with schizophrenia in the United States from 2.8 million to 750,000. With a change of the National Institute of Mental Health website in 2017, two million people with schizophrenia simply disappeared.

The 2.8 million estimate, or 1.1% of the adult population, had been the official standard for the U.S. since the 1980s, when the last major prevalence survey was carried out. The figure was provided to Congress in 1993 and used for national estimates such as the cost of schizophrenia.

25% Schizophrenia Curable Studies
Marie, SARDAA Team

With improvements in treatment approaches and newer medications, “Studies have indicated that 25% of those having schizophrenia recover completely” refers to various studies which I have provided as resources below. It is important to note that many of the studies found recovery completely from the first episode and there is much emphasis on early treatment that includes both cognitive and medication therapies.

The Interplay Between Genetics, Cognition and Schizophrenia
Maria Stella Calafato; Elvira Bramon

Schizophrenia is a severe mental disorder with a lifetime prevalence of 6.35 per 1000 (Moreno-Küstner et al., 2018). Multiple treatments
are available including antipsychotic drugs, psychological therapies and rehabilitation interventions. Although disease and treatment mechanisms are not fully understood, there is compelling evidence that schizophrenia is highly heritable with around 80% of its variance explained by genetic factors (Hilker et al., 2018). A mega-analysis of genome-wide association studies (GWAS) conducted by the Psychiatric Genomics Consortium identified more than a hundred genetic loci conferring susceptibility to schizophrenia (Ripke et al., 2014). While each individual single nucleotide polymorphism (SNP) carries only a subtle increase in schizophrenia risk (with odds ratios in the range of 1.1 to 1.2), their combination into a cumulative measure called the polygenic risk score (PRS) provides a stronger predictor of disease (Purcell et al., 2009). In this issue of Brain, Toulopoulou and co-workers explore the extent to which impairments in cognition mediate the influence of the PRS on schizophrenia liability (Toulopoulou et al., 2019).

**Sleep Disorders in Early Psychosis: Incidence, Severity, and Association With Clinical Symptoms**
Sarah Reeve; Bryony Sheaves; Daniel Freeman

Sleep disturbance is known to be associated with psychosis, but sleep disorders (eg, insomnia, nightmare disorder, sleep apnea) have rarely been investigated. We aimed to provide the first detailed assessment of sleep disorders and their correlates in patients with early psychosis. Sixty outpatients aged between 18 and 30 with nonaffective psychosis were assessed for sleep disorder presence, severity, and treatment using a structured diagnostic interview, sleep diaries, and actigraphy. Psychotic experiences, mood, and psychological wellbeing were also measured. Forty-eight patients (80%) had at least one sleep disorder, with insomnia and nightmare disorder being the most common. Comorbidity of sleep disorders within this group was high, with an average of 3.3 sleep disorders per patient. Over half of the sleep disorders had been discussed with a clinician but almost three-quarters had received no treatment. Treatment according to clinical guidelines was rare, occurring in only 8% of cases (n = 13). Sleep disorders were significantly associated with increased psychotic experiences, depression, anxiety, fatigue, and lower quality of life. Sleep disorders are very common in patients with psychosis, may have wide-ranging negative effects, and merit routine assessment and treatment in psychiatric practice.

**Schizophrenia’s Early Origins**
New information provides hope for reversing the disease in utero. Symptoms of schizophrenia typically don’t appear until young adulthood, but new research reveals that the disease likely starts well before birth.
Scientists at the University at Buffalo have found striking indications that the disease originates in early fetal development, through malformations in the cerebral cortex. That's the largest part of the brain, responsible for such critical functions as memory, cognition and language.

**Suicide: How You Can Make a Difference**
March 26, 2019
NIMH
The recent deaths of school shooting survivors have brought the topic of suicide into everyday conversations. This NIMH science update provides five action steps for helping someone in emotional pain. The update stresses the importance of knowing some facts about suicide and what people can do when they think someone might be at risk for self-harm.

**SAMHSA Report: Civil Commitment and the Mental Health Care Continuum: Historical Trends and Principles for Law and Practice**
SAMHSA recently released the report, Civil Commitment and the Mental Health Care Continuum: Historical Trends and Principles for Law and Practice in its Evidence-Based Practices Resource Center.

**SAMHSA Principles of Community-Based Behavioral Health Services for Criminal Justice Involved Individuals: A Research-Based Guide**
SAMHSA has released a new publication titled, Principles of Community-Based Behavioral Health Services for Criminal Justice Involved Individuals: A Research-Based Guide, which provides a foundation for realizing a quality, community-based behavioral health treatment system that is responsive to all individuals with mental and substance use disorders.

**Guidance on Strategies to Promote Best Practice in Antipsychotic Prescribing for Children and Adolescents**
The safe and effective use of antipsychotic medications for children and adolescents in the U.S. is a critical issue in mental and substance use treatment. This guidance provides systems-level strategies to inform public and private sector decision-makers, prescribing clinicians, and other key stakeholders in designing and implementing antipsychotic monitoring programs to improve outcomes for youth with mental disorders across the nation.
DTAC Bulletin: Disaster Planning and Preparedness and People with Serious Mental Illness

The current issue of the SAMHSA Disaster Technical Assistance Center (DTAC) monthly newsletter, DTAC Bulletin, is focused on materials and resources that are available to address the needs of individuals with serious mental illnesses in disaster planning and preparation efforts. READ MORE

Find Clinical Trial Participation by State:  HERE

NIH RESEARCH STUDY INFORMATION HERE

Schizophrenia Health Storylines™ Mobile App
Now it is easy to record details and specifics about symptoms, medication, moods, and more. Choose what you want to track, and see all the information you need to help you or your loved one who is living with schizophrenia and related disorders. Get the Schizophrenia Health Storylines™ Mobile App Today! The mobile app is FREE for all users on iOS and Android devices. There is also a web version available, accessible through the browser of any desktop computer or mobile device. Download the app today!

Donate to SARDAA

Help Support Schizophrenia and Related Disorders Alliance of America

Amazon donates to Schizophrenia & Related Disorders Alliance. Shop
Easy steps to support Schizophrenia and Related Disorders Alliance of America through Amazon Smile:

Sign in to your Amazon account at smile.amazon.com.

Select Schizophrenia and Related Disorders Alliance of America Search for and select Schizophrenia and Related Disorders Alliance of America as your charity. Once selected, you will receive a confirmation email.

Shop and checkout as you would on Amazon. No extra cost is passed on to you, but Amazon will automatically donate 0.5% of your purchases to Schizophrenia and Related Disorders Alliance of America.

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

By choosing Schizophrenia and Related Disorders Alliance of America as your charity on smile.amazon.com, Amazon will donate 0.5% of your eligible purchases to Schizophrenia and Related Disorders Alliance of America.

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 **XA142**
Help Change Lives -- Donate Now

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

Sincerely,
Angel White, Editor