Message from SARDA, CEO

Dear Friends,

We continue to pursue with great passion and commitment to reclassify schizophrenia spectrum to be formally recognized as the neurological brain disorder/illness that it is.
How do we accomplish this? By......

“Support and Treat”

Leading a Coalition to Create The Change
Join us on November 4, 2019 at Brains on Broadway to learn more and support our work.
Stay tuned for more exciting news to come!!

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

2:30 - 5:30 pm
COMPLIMENTARY SYMPOSIUM - Reservations required
Translation to Transformation
How We Can Help the Most Seriously Ill
Reclassification of Schizophrenia Spectrum As a Neurological Brain Illness
Panel Discussion and Speakers featuring world-renowned experts including:
Former Congressman Dr. Tim Murphy
Dr. Henry Nasrallah
Elizabeth Ford, MD
Elyn Saks, JD, PhD
Raymond Cho, MD, MSc
Clayton Chau, MD, PhD
Matcheri Keshavan, MD
Deborah Levy, PhD
Robert Laitman, MD

5:30 - 6:30 pm
VIP RECEPTION

6:30 - 8:30 pm
JOIN US FOR A STAR-STUDDED Benefit and Award RECEPTION
Featuring international recording artist Paul Taylor
Assistant Secretary Dr. McCance-Katz

$300 - Off Broadway Rate (until September 1st with discount code: EARLY)
$350 - Orchestra Rate (until November 4th)
$400 - At the Door

Please inquire at gordon.lavigne@sardaa.org about sponsorship opportunities and auction item donations.

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

Awareness Week is Almost Here!
Please Order your Schizophrenia Awareness Package by MAY 15th so you and can join thousands of people across the country speaking out and standing up for Schizophrenia Awareness in May.

Schizophrenia Awareness Week will be held from May 20 - 27, 2019 with World Schizophrenia Awareness Day on May 24th.

SARDAA has specially prepared Schizophrenia awareness items, all in one
package, to help you show your support for Schizophrenia this May.

**DONATE NOW** to order your Schizophrenia Awareness Package.

Schizophrenia Awareness Packages:
$30: Wristband & pen
$55: Wristband, pen & white t-Shirt

**MUST BE ORDERED BY MAY 15th**
Please stand in solidarity with those battling this disease by wearing your SARDAA Wristband or T-Shirt during the month of May. It’s a great conversation starter and key to getting others involved. [Click here to Donate Now!](#)

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**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](#)

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**Message from FFC, Families for Care, Coordinator**

This brings us to May, a month that highlights the importance of advocacy in mental health. Let us be aware of opportunities to move forward in our efforts of helping to find for those challenged with neuro-psychiatric disorders, a quality in life....an inalienable right.

In 1991, a decade following my daughter's diagnosis, I read a book which relates in part to meditation. Reviewing some notes I had made I see that I had begun the search, as a care partner, in support of my daughter's issues. A quote from a book by Sheldon B. Kopp, which must have been meaningful to me, states “Love is more than simply being open to experiencing the anguish of another's suffering. It is the willingness to live with the helpless knowing that we can do nothing to save the other from his (her) pain”. I am of the evolving belief that we all have our own path in life, we are born alone, pass alone, but during the time we have in life we have the opportunity to reach out and offer support, best we can and another is willing to
accept, to those with greater challenges in life. With respect to this, we must, very importantly, be mindful of tending to our own daily self care, as we so willingly provide for our loved ones. He/She will survive to the best of their ability, and as strength and support provide for them.

With Heart,
Mary Ross

Message from SA Staff Supporter
Hope
By Sandy Dimiterchik
I remember when I was first diagnosed with a brain disorder in 1998. I was in graduate school, and I was able to continue in my classes, even though I was being treated for what the doctor thought I had then - bipolar disorder. However, as my graduate work continued, I worsened and eventually had to withdraw from the university for medical reasons. It seemed like I had hit rock bottom, and I moved home. I was only expecting things to get worse. Then one day I remembered story I had always liked – Pandora’s Box. In the story Pandora is told to not open a box, and does. When she opens the box, out flies demons, and it just seems like it will not stop. Finally with all her strength she closes the box. Then she hears a voice saying “Open the box.” She does, and out flies a fairy, symbolic of hope. So, that story always reminded me that there is always hope, even when you think things can only get worse.

Today in a conversation I was asked when my recovery started. How you define recovery constantly changes. For me, it was when I was on the right medications, and also full of hope. I was able to hold down a part-time job and do some volunteering. However, my caretakers still needed to remind me about taking medication. Through the SARDAA app, Schizophrenia Health Storylines, you can be reminded to take your medication. This helped me increase my independence as I no longer needed to rely on others. Doing so gave me a renewed sense of hope, that my quality of life could improve. Like using a portable oxygen tank, I started doing more social activities because of my renewed confidence in being able to take care of myself.

Personal Story of Families for Care Members
Donna Kokulak
What did schizophrenia look like in my house?
It looked like a little boy who was very talented in sports and had
loads of friends. It looked like a 6th grade boy who got in trouble for touching a girl’s boob and his school district forcing a psychologist visit to clear his return to school. It looked like an 8th grade boy who no longer functions in mainstream academia, so he was placed in a “behavioral class”, in a different school. It looked like a high school boy who began to self-medicate with marijuana, all the while decreasing his self-esteem and confidence. It looked like a young man who was bullied quite often and as such, traumatized. It looked like a young adult who slowly alienated himself from his peers, while you as his mother did your very best to “protect” your son from the villains of this world.

READ MORE

Personal Story of SA Members
Jaapheth - Kenya SA
My mental health experiences in Kenya started in the year 2015. I had a serious psychotic breakdown that forced me to quit living in denial of the illness. I had been living in denial of being a paranoid schizophrenic since
I got diagnosed with the illness in 2005 in San Francisco. My family got involved for the first time in my illness and used quite unorthodox means for medicating me by putting the medicine in my food. I was not aware of this and only got to know about it in a later conversation with my younger brother. I did much better afterwards and was grateful. The downside to this was that they did not give me any medicine for depression and was hit hard by it. I was in a terrible shape depression wise. I started seeking help around where I live and soon realized that there was none. As a matter of fact, there was no psycho-social support group not only in the region but by and large in the whole Country.

I had lived in the USA and had a good experience with such a group in a clubhouse in San Francisco. So I felt the need to start one, and that was my first stint with becoming a mental health advocate in Kenya. Through the help of the then director of British Columbia Schizophrenia Society Deborah Conner, we organized and formed Schizophrenia Society of Kenya an organization that is now duly registered by the Kenya government. It took us a while to get registration which took place early this year of 2019 even though we came together as a group in 2016.

Since registration, we have started working with Siaya County Referral Hospital psychiatry department using a mixture of curriculum including the one by Schizophrenics Anonymous sponsored by Sardaa. We have also engaged the Siaya Government Prison to start doing the same and are waiting for a letter of authorization. We also hope to reach out to the schools, colleges and churches subject to funds being available. We do not have a single group sponsor and would like to find some for each group so please feel free to contact us if interested. We would like to spread across the whole Country. Currently, the group at SCRH is about 15 people but with group sponsorship for all the groups, we could reach over 300 a month.

I am also the Country representative of a newly formed global peer organization called Global Mental Health Peer Network and hope to change the mental health narrative into a positive one in the global stage. Please feel free to contact us at schizokenya@gmail.com

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**Prison Bars**

Bars of green and grey
Memories of my prison days
Shackles, Manacles, irons,
Ambulance, police car, sirens
They come attack beneath my eyes
As nightmares that will never die
Father Time, place them gently to rest
Lock them in your mighty chest
And let them fade there into the Abyss
These memories I will not miss
- Dylan K.

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

NEW MAILING ADDRESS:
SCHIZOPHRENIA AND RELATED DISORDERS ALLIANCE OF AMERICA (SARDAA)
2308 MOUNT VERNON AVE., SUITE 207
ALEXANDRIA, VA 22301-1328

Neurological Diseases Surveillance System—The Committee is pleased that CDC initiated developmental and implementation work for the National Neurological Conditions Surveillance System (NNCSS). The NNCSS will provide a foundation for the evaluation and understanding of neurological conditions by collecting information on incidence and prevalence, geographic clusters of conditions, demographic variability, outcome measures and health care practices and utilization. The Committee provides $5,000,000 within the total for Surveillance, Epidemiology, and Informatics to add at least one severe neuropsychiatric disorder, such as schizophrenia, to NNCSS implementation.

READ HERE

Researchers Seek 'fingerprints' of Severe Mental Diseases
Researchers from McLean Hospital and Yale University have published findings of their study of large-scale systems in the brain, findings that could improve understanding of the symptoms and causes of bipolar disorder, schizophrenia, depression, and other mental illnesses. Their paper, "Functional Connectomics of Affective

According to lead researcher Justin T. Baker, MD, Ph.D., scientific director of the McLean Institute for Technology in Psychiatry, the study "took a birds-eye view to look into the ways large-scale systems in the brain interact with one another." Baker and his colleagues used functional magnetic resonance imaging data from more than 1,000 individuals, including patients who had been diagnosed with conditions such as bipolar disorder, schizophrenia, and depression. Information was collected through rest scans, in which subjects were asked to simply lie in a scanner with their eyes open, allowing researchers to capture data about spontaneous fluctuations in the brain.

Nationwide Recruitment
A Study of Schizophrenia and the Brain: A Six-month Inpatient Evaluation Study
NIMH invites qualifying adults who have been diagnosed with schizophrenia or schizoaffective disorder to participate in an inpatient research study at the NIH Clinical Center in Bethesda, MD. In this study, researchers will be evaluating how the brain works in individuals diagnosed with schizophrenia to better understand the underlying causes of this illness.

This study is usually six months long and generally has three phases: The first phase involves a thorough evaluation of diagnosis, medications, and treatment. The second phase includes evaluations during periods on and off standard medications, with each period ranging from 4 to 6 weeks. The third phase focuses on stabilization, treatment, and discharge planning.

Evaluations include a variety of medical, cognitive, neurological, and neurocognitive assessments. Advanced neuroimaging techniques (e.g., MRI, MEG, and PET) are used along with specialized cognitive tests designed to understand specific functions of the brain.

Individuals who are interested in the study may email schizophrenia@mail.nih.gov or call 1-301-435-8970 (1-888-674-6464) [TTY: 1-866-411-1010] to find out if they qualify. 

Hit In The Head With A 2×4” Tim Murphy - My Personal Struggles Helped Put Life In Perspective
Pete Earley
May 6, 2019
“The Lord works in mysterious ways,” Tim Murphy told me.
When he was a member of Congress, he wielded power and enjoyed prestige - especially in the mental health community.

It was Murphy who held hearings immediately after the December 14, 2012 mass shooting of school children at Sandy Hook Elementary School in Newtown, Connecticut. (I testified at his first hearing about how the “imminent danger” criteria prevented me from getting my son help after I rushed him to a local emergency room.)

Murphy pushed for passage of the Helping Families in Mental Health Crisis Act, a bill he drafted. Its goal was to make mental health a federal priority. He faced strong and bitter opposition. He stepped on toes. Fought the status quo. Democrats blocked him. His first attempt died in committee. A CEO of a major mental health organization in Washington smirked and assured me Murphy's bill would never become law.

A Practical Guide to Psychiatric Advance Directives
This SAMHSA report provides background and practical information to those interested in promoting the use of psychiatric advance directives as a tool for promoting self-directed care in psychiatric treatment, making progress toward parity in mental health treatment, and supporting crisis planning and the rights of persons who live with mental illness.

Appointments to U.S. Preventive Services Task Force
The AHRQ seeks nominations to the U.S. Preventive Services Task Force. The Task Force works to improve the health of all Americans by making evidence-based recommendations about clinical preventive services, such as screenings, counseling services, and preventive medications. Each year, AHRQ's Director appoints new members to serve 4-year terms and replace those who are completing their service. Qualified candidates must demonstrate expertise and national leadership in clinical preventive services, critical evaluation of research, and implementation of evidence-based recommendations in clinical practice. Nominations must be received by May 15. The anticipated start for terms is January 2020.

In a Comparison of Two Kinds of Cognitive Training, One Appeared to Help Schizophrenia Patients More
A study just published in the American Journal of Psychiatry compares the two dominant approaches for treating cognitive deficits in people with schizophrenia, symptoms of the illness not addressed by antipsychotic medicines. It showed that both approaches were effective in addressing specific cognitive problems, but only one appeared to have benefits beyond the treatment period which translated into an enhanced ability of patients to function in the community.

Inpatient Stays Involving Mental and Substance Use Disorders, 2016
March 2019
Mental and substance use disorders are common in the United States. In 2016, over 55 million people aged 18 years and over (more than one in five adults) suffered from mental and/or substance use disorders (MSUDs).1 Of these adults, nearly 45 million had a mental disorder alone, 11 million had a substance use disorder alone, and 8 million had both a mental disorder and a substance use disorder.

Not only do mental and substance use disorders co-occur, they also are linked to other physical conditions such as diabetes, heart disease, and asthma.3,4 Disorders such as depression, anxiety, and substance use disorder are associated with significant distress and impairment, including complications with multiple chronic conditions, disability, inability to function in society, and substantial economic costs.5,6 The treatment costs of mental disorders alone totaled $201 billion in 2013.7 Taking into account additional costs associated with lost work productivity and disability payments, the total cost of mental and substance use disorders to society is estimated to be more than twice that amount.

Joshua A. Gordon, M.D., Ph.D.
NIMH Director
Each year, the lives of tens of thousands of teens and young adults are interrupted by an episode of psychosis. Symptoms of psychosis include delusions (false beliefs) and hallucinations (seeing or hearing things that others do not see or hear). It’s typical for a young person to have subtle signs of psychosis for some time before experiencing an episode of psychosis when their symptoms intensify and begin to interfere with many aspects of their lives. Their relationships with family and friends often become strained, and it may be challenging for them to work or go to school.

National Older Adult Mental Health Awareness Day Event
May 20, 2019, 1:00 pm – 3:30 pm ET, Washington, dc
SAMHSA, the Administration for Community Living, and the National Coalition on Mental Health and Aging are hosting an event in observance of Older Adult Mental Health Awareness Day 2019. Nearly 1 in 5 older Americans have one or more mental health/substance use conditions and older adults accounted for 18.2 percent of suicide deaths in 2016. This event is designed to raise public awareness around the mental health of older Americans and spur actions to address their needs by promoting evidence-based approaches to mental health and substance use prevention, treatment, and recovery supports for older adults and collaboration between the mental health and aging networks. It will also highlight where people can seek treatment and services when needed. A live webcast of the event will be available.

Nationwide Essay Contest Challenges High Schoolers to be Frank About Mental Health
NIMH
April 29, 2019 Press Release
Suicide is the second leading cause of death for youths aged 15 to 24, yet only about half of young adults with a mental disorder receive treatment. In an effort to address this disparity and further conversations about mental health among high schoolers, the National Institutes of Health invites students ages 16 to 18 years old to participate in the “Speaking Up About Mental Health!” essay contest. Essays should explore ways to address the stigma and social barriers that adolescents from racial and ethnic minority populations may face when seeking mental health treatment. The contest is led by the National Institute of Mental Health (NIMH), in collaboration with the Calvin J. Li Memorial Foundation, and the National Institute on Minority Health and Health Disparities (NIMHD). NIMH and NIMHD are components of NIH.

“Teens have important stories to tell about their experiences with mental health treatment, and we hope this contest will give them an
opportunity to express their thoughts and ideas. It’s clear we need to work with them to better understand mental health stigma and the barriers they may face when seeking mental health treatment,” said Joshua Gordon, M.D., Ph.D., director of NIMH.

NIH Brain Initiative Tool May Transform How Scientists Study Brain Structure and Function
April 17, 2019 Press Release
Researchers have developed a high-tech support system that can keep a large mammalian brain from rapidly decomposing in the hours after death, enabling study of certain molecular and cellular functions. With funding through the National Institutes of Health BRAIN Initiative, researchers developed a way to deliver an artificial blood supply to the isolated postmortem brain of a pig, preventing the degradation that would otherwise destroy many cellular and molecular functions and render it unsuitable for study. Importantly, although the researchers saw some preservation of flow through blood vessels and energy use, there was no higher level functional activity in the brain circuits. The scientific team, led by Nenad Sestan, M.D., Ph.D., of Yale University, New Haven, Connecticut, reports on their findings in the journal Nature.

Tailored Program Might Help Some with Severe Mental Illness Quit Smoking
Anne Harding
April 19, 2019
NEW YORK (Reuters Health) - A smoking-cessation program tailored to people with schizophrenia and bipolar disorder may help some quit, new findings show.
"It doesn't disrupt their mental health. In fact we know from research that the opposite is true. Quitting smoking is really good for your mental health," Dr. Simon Gilbody of the Mental Health and Addictions Research Group at the University of York, in the U.K., told Reuters Health by phone.

Smoking is much more prevalent among people with severe mental illness, who also start smoking earlier and smoke more heavily than people in the general population, Dr. Gilbody and his team note in The Lancet Psychiatry, online April 10.
Need Help" Don't miss this opportunity to learn about the LEAP communication technique.

**GET more information**
**Register HERE**

Find Clinical Trial Participation by State:  [HERE](#)  

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**NIH RESEARCH STUDY INFORMATION HERE**

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**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!**

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**Donate to SARDAA**

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**Help Support Schizophrenia and Related Disorders Alliance of America**

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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.

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.

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**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

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**Help Change Lives -- Donate Now**

Thank you to those who already made a donation. Every contribution makes a difference.
Sincerely,
Angel White, Editor