Message from SARDA, CEO

Dear Friends,

We just celebrated July 4th, Independence Day the day we rejoice in the USA’s Liberty and Freedom.

However, our loved ones, colleagues, neighbors and friends who are affected by schizophrenia related brain illnesses aren’t beneficiaries of the equitable liberty and freedom for the pursuit of health, happiness and success.

Liberty is “the state of being free within society from oppressive restrictions imposed by authority”. Since appropriate treatment and adequate research is not as available for “our” community, liberty is not their experience. The inequitable opportunity for treatment denies people the freedom to experience a successful and meaningful life others enjoy.

Become a hero and help all affected by psychosis, write to The Senate Appropriations Leaders and implore the passage of joint FY2019 Defense and Labor, Health and Human Services and Education Appropriations Act as passed by Congress to establish the National Neurological Conditions Surveillance System (NNCSS). The language of the Act is as follows:

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.

We require accurate data to better understand schizophrenia and provide the vitally
important research and treatment for our most untreated and underserved fellows.

You can use some of this language in your letter: Fervent efforts to help the very most rejected, brutalized and
untreated of our fellows, those suffering with a neurological brain illness that we call schizophrenia. We don’t brutalize and treat barbarically those who are diagnosed with Parkinson’s Disease nor MS, but we do to people who are diagnosed with schizophrenia. Symptoms of Alzheimer’s and Parkinson’s are similar, but are evident late in life versus the horrific symptoms that young people with schizophrenia experience. As you can see from the attached chart, there are similarities, but the differences in treatment and care are stark and inhumane!

If we don’t change the paradigm through the recognition that these are neurological brain illnesses, not elective disorders and secure accurate statistics to reflect the realities, we will continue to leave loved ones untreated, homeless, incarcerated and relegated to an early death.

Write to:

The Honorable Roy blunt
Chairman
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States of America
Washington, D.C. 20510

The Honorable Patty Murry
Ranking Member
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States of America
Washington, D.C. 20510

Very best,
Linda Stalters, MSN, APRN (ret)
Chief Executive Officer
Schizophrenia and Related Disorders Alliance of America
2:30 - 5:30 pm
COMPLIMENTARY SYMPOSIUM
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
    Jeffrey Lieberman, MD
Complimentary with Registration

5:30 - 6:30 pm
VIP RECEPTION by invitation only
International Recording Artist Paul Taylor

6:30 – 8:30 pm
JOIN US FOR A STAR-STUDED AWARDS RECEPTION

    Honorary Chair: Glen Close
    Keynote Speaker: HHS Assistant Secretary Dr. Elinore McCance-Katz
    International Recording Artist Paul Taylor

$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 angel.white@sardaa.org for information and auction item donations.

**Funded by: Ann Allen Cetrino Family Foundation**

[Button: Purchase Tickets]

**Purchase Your Brains on Broadway Tickets Now!**

**Limited Space Available**

**Early Registration Discount until September 1st with Code:** EARLY

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**Shout out to folks living in and around New York City. Schizophrenia and Related Disorders Alliance of America (SARDAA) is in need of volunteers for our upcoming, Brains on Broadway event coming November 4, 2019 at The Westin New York at Times Square. This spectacular event begins with a symposium from 2:30 p.m. to 5:30 p.m. followed by a star-studded reception from 6:30 p.m. to 8:30 p.m. Hot topics include the reclassification of schizophrenia for future research and treatment and how we can help improve lives affected by psychosis.**

**Can we count on your support for this exciting event? A fantastic opportunity for you to learn more about brain illnesses while meeting some amazing people.**

**If you are interested in volunteering for this special event please contact Mary mary.troy@sardaa.org or Angel angel.white@sardaa.org or 240-423-9432.**

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

Searching...I always have, throughout my daughter's journey with SMI. Beginning with questioning 'if a person has but one life, how
can it be so challenged’? Dwelling on the seeming unfairness of it, I came to know that she is but one of many challenged with a disability or other really tough things in life. It helped me to move on, resolve the anger I felt. This was followed by years of hoping for improvement, always looking for that something that was going to make things somewhat better, to see her onto a more positive path. It hasn't come, hopes dashed....again. She has not been one of those fortunate to find their way onto the recovery path, which is not a cure at this time, rather a state of 'doing one's best'. That passed. My understanding at this point is that because it is not my diagnosis, my challenge, I am not able to fix it...it is her life and hers to deal with, best she can, and that I'll always be there in support. It is the sadness that is mine to bear. Of late I've become aware of a type of thinking which says 'sometimes in life there just isn't an answer, at least not currently'; also, regarding times or instances of ambiguity in life, to strive to be more comfortable with uncertainty. There is a peace in this state of 'just letting be'. I saw a bumper sticker which read 'This isn't the life I ordered', which may be a sentiment shared by some. Related, a quote by Joseph Campbell says “We must let go of the life we had planned so as to accept the one that is waiting for us”. It is a journey, and I believe we are stronger for it, even if it isn't readily known.

In Heart,
Mary Ross

Message from SA Staff Supporter
Spirituality and Schizophrenia Alliance:
Psychosis Support and Acceptance Groups

By Sandy Dimiterchik

According to Merriam-Webster Dictionary, one definition of spiritual is “of, relating to, consisting of, or affecting the spirit.” What is the spirit? That word is argued over by the greatest minds. According to my Louisiana certified Peer Support Specialist Training, spirituality provides meaning and purpose, and quoting the book we used, Peer Employment Training: A Peer /Recovery Support Specialist Certification Course by RI International, “Spirituality is a very personal issue, so we approach it respecting each person’s experiences and chosen path. (Page 18).” The book goes on to say, “For many, a family, a pet, a job, art work or writing might be where (the person finds) meaning and purpose. (Page 21).”

Step 6 of the Blue Book provides some input: I Decide ... I make a
decision to turn my life over to the care of a Higher Power, as I understand the Higher Power, surrenderring my will and false beliefs. I ask to be changed in depth.

As a facilitator, it is important to keep discussion on the Higher Power. In fact, the Blue Book states on page 10 of the 2019 version: “Abusive talk is not tolerated nor are discussion of illicit drugs, or discussion of sex, politics, or religion.” At SA meetings, we welcome people of all different views, and don’t hold discussions about religion. People who are atheist, agnostic, or who hold other views are welcome to the meetings. The meetings are not a time to witness or convert people to your own views.

Personal Story of SA Members
Rob R.
My name is Rob R. and I am diagnosed with Schizoaffective Disorder. When my symptoms get severe, I experience voices, hallucinations, delusions, depression, and severe anxiety. Back in 2016, I had a horrible breakdown on my then boyfriend, leaving me paralyzed with fear and suicidal... Michael, my now husband, was at a loss as to what needed to be done. He had very little experience with mental illness and the symptoms that can occur when someone is having an episode. Michael was aware that I am a very naturally creative person. In the middle of my crisis he did the only thing he could think of. He took me to an art supply store and bought me some canvas and paints. This was his way of giving me something that would take my mind off my problems, and hopefully relieve some of the anxiety.

The day we bought the art supplies I went home and did something that changed my life. I started painting. This was art that I had never tried before so it was challenging yet fun at the same time. I would spend hours working on a piece, pouring all my emotions and mental chaos into the painting. By the time I was finished, I had a truly remarkable piece. The more I painted, the more I developed my own style, the more I feel in love with the craft. Friends and family started asking for my art and had even commissioned me to create individualized pieces. This was a thrill.

As time went on, I noticed that my mental illness symptoms diminished as I painted. I would get lost in a painting and the hallucinations and anxiety would somehow vanish, even if for a couple of hours. This was a lifeline to me! When I would have an emotional episode, I would go to the canvas and paint out what I was feeling. Every time I painted, I found myself getting a little stronger and not feeling as helpless as I had felt in the past. My creativity had become a tool for me to combat my mental illness and I felt free for the first time in a long time.
I wanted to write this short article to give others hope. Anyone dealing with a mental illness knows how difficult the battle can be. I firmly believe in medicine and therapy to help, but I also believe that sometimes our passions for art, music, sports, theatre, etc. can be a powerful tool in diminishing the symptoms that come with illness. I have found joy in painting, but the chosen outlet can be different for everybody. Not only is my art great therapy for me, but it has become a means for me to make a little money and get some great exposure as an artist.

I hope that my story can show others that artistic outlets are very effective in combating mental illness.

-Sardaa needs your vote!
Times have changed since SA started in 1985. Now diagnosed individuals can work as peer support specialists for different organizations that pay for their services.

Should we allow SA group leaders to be paid by third-party organizations? SARDAA will not be paying SA Leaders, but sometimes places where Leaders work will include SA as part of their responsibilities, local organizations or government sometimes offer a stipend for people when they are providing service.

These changes could result in more SA groups and the opportunity for more diagnosed individuals to participate in face to face SA groups.

The question you are voting on is: **May SA Group Leaders receive compensation by**
third-party organizations for leading a group?
Yes or No

Please send your vote to Sandy, sandy.dimiterchik@sardaa.org

Thanks!
Sandy Dimiterchik
sandy.dimiterchik@sardaa.org
240-423-9432

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

**Beatitudes for Caregivers**
Blessed are those who sleep poorly because they’re worried about their loved one or because their loved one wakes in the middle of the night and needs help, for theirs is the kingdom of heaven.
Blessed are those who mourn because their loved one, though still alive, is slipping away because of psychosis, for they will be comforted.
Blessed are the meek who force themselves to speak up and speak out to make sure their loved one receives the help he or she needs, for they will inherit the land.
Blessed are those who hunger and thirst for answers to why this is happening to their loved one and how much longer it will go on, for they will be satisfied.
Blessed are those who show mercy, kindness and compassion to their loved one, for they will be shown mercy, kindness and compassion.

READ MORE

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Book Review of *Experiencing & Overcoming Schizoaffective Disorder* by Steve Colori
By Sandy Dimitrichik

Have you ever wondered what it is like to have schizoaffective disorder? What kind of thinking the person has or how the person might react to different situations? What about the kind of relationships the person has?

*Experiencing & Overcoming Schizoaffective Disorder* is a good book to read, whether a person also has the illness, knows somebody who does, or wants to learn more about the illness. The author, Steve Colori, describes what it feels like and what kind of thoughts a person can have who has the disorder. The book also shows things that can possibly hinder a person who is trying to achieve goals, like receiving an education, while inspiring the readers that those goals can be pursued and achieved.

Another thing I was impressed with was the degree of detail the author showed to describe how therapy can be an asset. I have heard of journaling before, but the author was able to correct his thoughts and identify the kind of thoughts they were. I think that there is a lot that can be done in therapy, even if the
person suffers from psychosis.

This book would be a good book to discuss in SA meetings. Although it is about schizoaffective disorder, I think some of the author’s symptoms have commonality with other disorders, like schizophrenia, bipolar disorder, depression with psychosis, experience with psychosis, and OCD. The book can be found on Amazon at https://www.amazon.com/Experiencing-Overcoming-Schizoaffective-Disorder-Memoir/dp/1512144363.
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
research on not only psychosis but also schizophrenia and bipolar disorder.

**Brain Study Reveals Type of Schizophrenia similar to Neurodegenerative Disease**
Rich Haridy, Johns Hopkins Medicine
June 24, 2019
Research from Johns Hopkins Medicine has revealed some cases of schizophrenia can be associated with abnormal protein buildup in the brain similar to that seen in cases of Alzheimer's and other neurodegenerative disorders. It's hoped the discovery will lead to better diagnostic strategies identifying specific types of schizophrenia.

**Estrogen a Possible Treatment Option for Women with Schizophrenia?**
Caroline Cassels, Medscape Medical News
May 23, 2019
Elise Turner, MD, and Viviana Alvarez Toro, MD
A systematic literature review conducted by investigators at the University of Maryland in Baltimore showed the addition of estrogen reduced schizophrenia symptoms in a dose-dependent, and statistically significant, manner compared with standalone antipsychotic treatment.
"Our review suggests estrogen has a significant effect in terms or improving psychotic symptoms, so I think this finding is very encouraging and that it needs to be explored further in additional studies," study investigator Viviana Alvarez Toro, MD, told Medscape Medical News.

**Evidence Links Abnormally Formed Proteins With Schizophrenia Pathology in Some Patients**
Brain & Behavior Research Foundation
Abnormally formed proteins may be involved in the pathology that causes schizophrenia in a subset of patients, new research suggests. A team led by 2013 and 2010 BBRF Young Investigator Frederick Nucifora, Ph.D., D.O., M.H.S., of Johns Hopkins University School of Medicine, and including seven other BBRF grantees, published their findings in the American Journal of Psychiatry. The team analyzed postmortem brain tissue from 42 schizophrenia patients, donated by brain banks at three different institutions. They compared these with postmortem brain samples (from the same collections) of 41 people who had not been diagnosed with schizophrenia. Having samples from different collections enabled the team to test and retest their results for consistency.
More Evidence Endorses Benefits of Long-Acting Antipsychotics
Pauline Anderson, Medscape Medical News
June 10, 2019
Results of new research further highlight the advantages of long-acting injectable antipsychotics (LAIs) over oral medications for patients with severe schizophrenia.
Two studies presented here at the American Psychiatric Association (APA) 2019 annual meeting suggest that use of these agents leads to improved adherence and a reduction in suicide attempts for these patients.
Physicians should be aware of the emerging research underlining the benefits of LAIs, the author of one of the studies, Olaniyi O. Olayinka, MD, resident psychiatrist, Department of Psychiatry and Behavioral Sciences, Interfaith Medical Center, New York City, told Medscape Medical News.
"With regard to relapse and readmission rates, the evidence suggests that LAIs have increased efficacy," Olayinka said.

Protein Buildup in the Brain a New Target for Schizophrenia?
Megan Brooks, Medscape Medical News
July 3, 2019
Protein buildup in the brain, similar to that seen in the brains of patients with Alzheimer disease and Parkinson disease, may be a pathologic mechanism for some cases of schizophrenia. The finding could lead to the development of novel treatments for the disorder, new research suggests.
"Researchers have been so focused on the genetics of schizophrenia that they've not paid as much attention to what is going on at the protein level and especially the possibility of protein aggregation. This may be a whole new way to look at the disorder and develop more effective therapies," lead investigator Frederick Nucifora Jr, PhD, assistant professor of psychiatry and behavioral sciences at the Johns Hopkins University School of Medicine in Baltimore, Maryland, said in a news release.
The study was published online May 6 in the American Journal of Psychiatry.

DOD Officials urge Troops to Seek Mental Health Help Without Fear
This Department of Defense (DOD) article highlights the DOD’s remarks to lawmakers during a joint hearing of the House Armed Services Committee's subcommittee on military personnel and the House Veterans Affairs Committee's health subcommittee that
solving suicide is a shared challenge in both the military and civilian societies.

**NIH Research Matters: Language Patterns May Predict Psychosis**
June 25, 2019
The current issue of this newsletter highlights a proof-of-concept study in which spoken language patterns predicted which people at risk for psychosis would progress to full psychosis within two years with 93% accuracy.

**Finding Help Early: Community Education Strategies for Clinical High Risk and Early Psychosis**
May 9, 2019
The SAMHSA National TA Network for Children’s Behavioral Health (TA Network) Telegram recent SAMHSA-sponsored webinar.

**SAMHSA: Forensic Assertive Community Treatment (FACT): A Service Delivery Model for Individuals with Serious Mental Illness Involved with the Criminal Justice System**
This brief provides an overview of Forensic Assertive Community Treatment — an intensive service delivery model intended for people with serious mental illnesses who are involved in the criminal justice system.

**SAMHSA: Screening and Assessment of Co-occurring Disorders in the Justice System**
This report provides evidence-based practices for screening and assessment of adults in the justice system with mental illness, substance use disorders, or both. It discusses the importance of instrument selection for screening and assessment and provides detailed descriptions of recommended instruments.

**SAMHSA: Tailoring Crisis Response and Pre-Arrest Diversion Models for Rural Communities**
This action brief provides rural communities recommended strategies for adapting promising or proven interventions to better support crisis response and pre-arrest diversion in their communities. It is the first of three briefs developed from the SAMHSA Pre-Arrest Diversion Expert Panel.

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

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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
Link to: Schizophrenia and Related Disorders–Kroger Plus Card XA142

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

Sincerely,
Angel White, Editor