Message from SARDAA, CEO

Dear Friends,

January brings thoughts of new beginnings, broadening opportunities and continue successes. Our staff and Board of Directors are diligently working on our vitally important efforts to:
- Quantify the costs of not treating individuals living with schizophrenia spectrum brain illnesses
- Develop and expand SARDAA Chapters
- Magnify our coalition to reclassify schizophrenia spectrum as a neurological brain illness
- Influence the development of a comprehensive continuum of life-long care for individuals with brain illnesses and eliminate homelessness and incarceration
- Advocate for compassionate communication within HIPAA so caregivers, including families, to provide access to appropriate care
- Advocate for the elimination of the IMD Exclusion
- Advocate for programs that will incentivize more brain health specialists (i.e. Advance Practice Registered Nurses, NeuroPsychiatrists, Psychiatrists, Psychologists)
- Promote smoking cessation

We are proud to announce two new enthusiastic and well-qualified SARDAA Members to the Board of Directors: Angela Babaev and Kurt Talbot. Both Angela and Kurt are deeply committed to the mission of SARDAA and have immediately immersed themselves in working to improve lives affected by psychosis.

We are so very excited to continue the Brains on Broadway discussion. We are on the way to Brains on the Beach on the Hollywood Beach Broadwalk, Florida. SAVE THE DATE March 21, 2020 for Translation to Transformation, Chapter 2. You will be able to register within the next two weeks for an exciting and much anticipated opportunity to meet and work together on how we can create a change in the treatment paradigm.

Announcing an exciting contest! The first person who emails angel.white@sardaa.org with the name of the resort that Brains on the Beach will be held will receive two free registrations for the Symposium total value of $90.00! Submissions accepted through January 12, 2020. (not including hotel, travel or reception) *SARDAA Board, Staff and Committees are excluded.

See you very soon in Hollywood!

Linda Stalters, MSN, APRN (ret)
Chief Executive Officer
Schizophrenia and Related Disorders Alliance of America
Message from FFC, Families for Care, Coordinator

As an artistic, creative, also challenged, and fun loving friend of mine commented at the start of this New Year, “The roaring ’20s are here”. None of us were here during the 1920s to remember, but I enjoyed her lighthearted intent. Beginning this New Year, I’d like to share, as was shared with me, the uplifting song ‘A New Year’, written by Michael Hunter Ochs in 2016, which “grounded in Jewish liturgy, is also universal in its message and optimism”. This song, as sung by cantors, rabbis and Jewish congregation members, can be enjoyed HERE.

In Heart,
Mary Ross
Message from SA Staff Supporter

Training Manuals for Potential SA Group Leaders

By Sandy Dimitarchik

With the New Year for 2020, it is a good time to set goals. Maybe you can get a daily meditation to read and start off your day. Perhaps you are interested in starting one of our support groups for people diagnosed with schizophrenia or related disorders, including bipolar disorder, schizoaffective disorder, depression with psychosis, or experience with psychosis. These groups are call SA or Schizophrenia Alliance: Psychosis Support and Acceptance. Though we prefer you have a diagnosis yourself, people can start groups, what we call Pro Supporters, with the intent of finding a leader in the group as soon as possible.

One of the biggest obstacles may be finding a location. We actually have different group manuals based on where your SA group is located. The Group Leaders’ Manual for Secured Environments is for SA groups located at hospitals or prisons. There is a requirement of somebody overseeing the groups affiliated with the organization. The Groups Leaders’ Manual is for everybody else. In both, we suggest places for locating your groups and roles and responsibilities.

Both settings use the Blue Book, our user manual that provides a meeting template and lists the 6 Steps of Recovery and includes a commentary on each. There are other articles in the book and over 50 personal recovery stories about how SA helped a member or members.

For more information, please contact me at 832-439-1586 or sandy.dimiterchik@sardaa.org.

Nominations for SARDA Annual AWARDS

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

Please submit your nomination no later than
February 10, 2020

Award Criteria and Application

SARDAA needs volunteers!

Social Media Team
Are you or someone you know a Social Media expert?
Join the SARDAA Social Media Team!
View Requirements HERE

Call Center Team
We are seeking volunteers experienced in working with individuals and their loved ones affected by psychosis brain illnesses to answer phone inquiries.

Communications Team
We are seeking volunteers to assist the Communications Team making calls to build database for resources.

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

Personal Story of SA Members

Lázló

I was 39 when psychosis first struck. We lived in our new, three-story house, on the top of a hill, pretty isolated, especially in winter. My partner was expecting our first child. It was a cold January day, we were about to have lunch when the phone rang. It was her mother, announcing the death of his ex-husband.

We immediately packed our things. We had to go to the morgue to take the clothes. It was only me who wanted to see the body: he was there lying, naked, together with another relatively young man, the chest sewn up, and I was sure that, if they hadn’t performed an autopsy, I could have woken him up by touching him. It was the first time I felt this magic power growing in me.

From the first night spent there I stopped sleeping and I had a fever of 38 degrees Celsius, so I began to think. My non-sleeping continued when, at last, we could go home after the funeral. In a normal state I am withdrawn: now I was active all the time: I was thinking, speaking without stopping. I looked for connections in everything. I wrote a lot, but so quickly that nobody could read it. I was extraordinarily attracted to books. I knew I had a mission. At night I didn’t let my pregnant partner sleep, I had to share my newest theories with her about world peace. I made a huge telephone bill calling my old teachers, the prime minister (in vain, of course), I even wanted my French friend to help me contact their president. She tried to call the family doctor to ask for help, but he never came up. She was having a mortal fear. When I went down to the village to look for company, I shook hands with people for a long time, hugged them to give energy and spoke to them strangely, for example about billions of dollars I would get from America for my plans to save the world.

I took a taxi to go home. I was extremely exhausted by then, but I went to the local supermarket. What I touched accidentally I immediately put in the basket: cat food, Guiness. At the cash desk, I said I was not going to pay because money wasn’t worth anything anymore. I had to leave everything there but they reported me. Soon the police came to our place and they saw what was happening. By that time all I wanted to do was to sleep. They took me to the doctor who, so far, refused to come up the hill, he gave me a shot and, for the first time after two weeks, I was able to sleep a little. The following day my friends organized to take me to the hospital, saying, an old classmate of mine working there is ready to discuss about the imminent changes in the world. That’s how I found myself in the psychiatry.

I stayed there for six weeks. My diagnosis was schizophreniform psychosis, later they called it schizoaffective
disorder. When my son was born, healthy, I was present. We had to go back to the hospital for checkup about three times until my medication was definitively stopped. We tried to live in a normal way again, hoping that this episode developed a lot more quickly, partly because of a medicine change and a really big stress. Soon another one...This time I lost my job, my employer didn't trust me anymore.

For five years I have been all right again. I don't want to stop taking medicine any more. I live with my girlfriend in the town I moved soon after my divorce to follow my son I have always had a normal relationship with.

I am a member of the local SA group. Our young psychiatrist gave the idea years ago, together with a community foundation that looks after us, who have a schizophrenia-related illness. I help them by translating books from English to Hungarian.

We are not alone anymore!

A Book Review of *The Center Cannot Hold: My Journey Through Madness* by Elyn R. Saks

By Sandy Dimiterchik, SA Staff Supporter

Elyn Saks, the author of *The Center Cannot Hold: My Journey Through Madness*, has accomplished many goals that few people have, with or without a brain disorder. As a graduate of Vanderbilt University, she also received at Oxford University her masters of letters and at Yale Law School her J.D. Finally, at the New Center for Psychoanalysis she obtained a Ph.D. in psychoanalytic science. She is currently a professor at the University of Southern California Gould Law School.

Her autobiography describes her journey to obtain these things while suffering from schizophrenia. It is a book that I feel many people with a diagnosis of schizophrenia or related disorders can relate to in terms of how difficult it is to go on medication and have side-effects, including fatigue. It is good to remember that people without a brain disorder also find these goals hard to meet.

As a certified peer support specialist, I share my lived experience of having a brain disorder with others. I went to graduate school twice and due to the onset of my illness was unable to complete graduate work. I know other people with a later onset or while on medication who were able to complete their Master’s degrees. The question I had when reading this book is when is the brain disorder too serious to complete school or work without medication? When do we force medication on a person if they are able to meet such goals? Should there be a so-called “safety net” so that people are able to further their education, and how can the schools help the person? There is a place for accommodations, through ADA, and that should be known to all students.

I completed the book quickly, though I am still left with questions that I am not the one to answer. This would be a good book for students to read, and have them come up with their own answers. Perhaps SA leaders could recommend it to SA members, families, friends, and other advocates.

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**Become a SARDAA State Chapter Lead, State Chapter Member, or Families for Care Group Leader**

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? Leading a local Families For Care support group? Helping other families in their journey through brain illness?

Please 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!
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

Coming Soon! Spanish Speaker's Families For Care - Monday evenings
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 SA Support
JOIN The Facebook Group Here

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

For Caregivers and Diagnosed individuals
SARDAA Support
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
SARDAA has chosen eBay for Charity so you can directly support SARDAA when you sell and buy items on eBay.

**Auction Items to Benefit SARDAA**

**EBAY FOR CHARITY**

1. **IN THE LISTING FLOW, SELECT THE OPTION TO “DONATE A PORTION TO CHARITY”**

2. **SELECT SARDAA**

3. **SELECT THE PERCENTAGE YOU WOULD LIKE TO DONATE**
   - You can verify the charity and donation percentage on your item by checking the information included in the item description.

4. **SARDAA will be notified of your listing according to its account preferences and has the right to request an item cancellation if it prefers not to benefit from your listing.**

5. **SELL AND SHIP**

**PAYPAL**

**PAYPAL GIVING FUND**
Congratulations to Sr. Lucindia, SA Group Leader!
December 17, 2019 was proclaimed as Sr. Lucindia Claghorn Day in Mobile, AL. Sr. Lucindia Claghorn was honored by the Mobile, Alabama City Council for her 30 years as a Nun in the community.

Webinar: Meet the Scientist
Using Tools of Neuroscience to Make Personalized Care a Reality in Schizophrenia
January 14, 2020, 2:00 - 3:00 PM EST
Presented by Gregory A. Light, Ph.D.
Dr. Light will describe precision medicine trials his team has conducted which significantly reduced...
symptoms and improved cognitive and daily functioning in patients with chronic psychosis in a “real-world” setting: a long-term community inpatient facility. They also found that reliable, easy-to-obtain signatures of brain-wave activity recorded at the outset of treatment can be used to identify which patients are most likely to benefit (or not) from treatments. This work ultimately aims to develop personalized biomarker assessment tools to deliver the “right treatment” to the “right person” at the “right time,” to improve outcomes among the millions of people with psychotic disorders, most notably schizophrenia.

Thank you DJ Jaffe for your work speaking up for the most seriously neuropsychiatrically ill on FOX and Friends. DJ Jaffe, executive director of Mental Illness Policy Org. Watch video HERE

**Emotion Recognition Related to Functional Outcomes in Those at Risk for Psychosis**

Celeb Rans  
December 13, 2019  
Degraded Facial Affect Recognition task accuracy at baseline did not differ significantly between healthy controls and the entire clinical high risk group. In individuals at clinical high risk for psychosis, difficulties recognizing negative emotions may play an important role in poor functional outcomes, according to case-control study results published in JAMA Psychiatry. However, the study reported no findings distinguishing the entire clinical high-risk group in terms of gray matter volume.  
READ MORE

**FDA Approves Intra-Cellular Therapies’ Novel Antipsychotic, CAPLYTA® (lumateperone) for the Treatment of Schizophrenia in Adults**

December 23, 2019  
Global Newswire  
Intra-Cellular Therapies, Inc. (Nasdaq:ITCI), a biopharmaceutical company focused on the development of therapeutics for central nervous system (CNS) disorders, today announced that CAPLYTA® (lumateperone) has been approved by the U.S. Food and Drug Administration (FDA) for the treatment of schizophrenia in adults. The Company expects to initiate the commercial launch of CAPLYTA in late Q1 2020.  
READ MORE

**Few Grey Matter Abnormalities Found in Individuals at High Risk for Psychosis**

December 13, 2019  
Sheila Jacobs  
There were no significant differences in grey matter intensity or cortical thickness observed among clinical high-risk participants compared with individuals who were clinical high-risk-negative and healthy controls.  
READ MORE

**Imaging Study Links Changes in Function and Structure of the Hippocampus in Early Psychosis**

Brain & Behavior Research Foundation  
Stephan Heckers, M.D.  
November 21, 2019  
An imaging study links reductions in the size of the anterior hippocampus with hyperactivity in that region seen in early-stage psychosis patients. The finding informs efforts to develop interventions to delay or even prevent psychosis.  
READ MORE

**Improving Treatment Adherence in Schizophrenia: Long-Acting Injectables**

Tori Rodriguez, MA, LPC  
December 13, 2019  
Long-acting injectable antipsychotics are effective in patients with schizophrenia who often exhibit deficits in executive functioning that affect administration of medications.  
READ MORE

**Is Marijuana Linked to Psychosis, Schizophrenia? It’s Contentious, but Doctors, Feds Say Yes**

USA Today Network  
Trevor Hughes, Stephanie Innes, Jayne O’Donnell  
Early one morning in March, Madison McIntosh showed up on his day off at the Scottsdale, Arizona, driving range and restaurant where he worked. The 24-year-old sat in his car until the place opened, then wandered around all day, alternating between gibberish and talk of suicide as co-workers tried to keep him away from customers.  
READ MORE

**OCR, DOE Updates Privacy Guidance on Sharing Student Health Records**

The updated DOE and OCR guidance for HIPAA and FERPA sheds light on common privacy
applications to student health records, like when it’s appropriate to share PHI during an emergency. 
Jessica Davis  
December 19, 2019  
The Department of Education and the Office for Civil Rights released an update to both the Family Educational Rights and Privacy Act (FERPA) and HIPAA, addressing the privacy applications to the records maintained on students.

READ MORE

Prediagnosis Healthcare Utilization May Aid Earlier Schizophrenia Detection
Psychiatry Advisor Contributing Writer  
November 5, 2019  
Before being diagnosed with schizophrenia a patient profile based upon healthcare usage data might indicate an opportunity for intervention among healthcare professionals.

READ MORE

Psychiatric Patients Are Suffering From Our Mental Health System
John Snook, Executive Director, Treatment Advocacy Center  
Media Planet, Men’s Mental Health  
“We must stop dooming people experiencing severe mental illness to needless suffering. We should give them a bed instead.” America’s mental health treatment system is broken. Those most in need struggle to find care, frequently ending up homeless, victimized or incarcerated. Even bedrock aspects of the system are now completely dysfunctional. The crisis-level shortage of psychiatric treatment beds is a prime example — and one that has tragic consequences.

READ MORE

Shared Genetic Liability Observed for Schizophrenia, Psychosis in Alzheimer Disease
Emily Pond  
November 21, 2019  
As study limitations, investigators noted the variability inherent in using several study cohorts, rather than a single sample. Psychosis in Alzheimer disease (AD) may share genetic liability with schizophrenia, according to an article published in Translational Psychiatry. The study raises the prospect of a transdiagnostic approach to psychotic symptoms across the lifespan.

READ MORE

What if Pictures of Your Brain Could Predict Schizophrenia?
Laura Castañón  
November 26, 2018  
Your brain is always working. Even as you’re lying still, thinking of nothing in particular, blood is rushing oxygen to different areas of your brain, creating a network of activity. Through brain imaging, researchers can watch this resting activity rise and fall in different regions. Some areas will fluctuate together, like pairs of dancers moving to the same beat.

READ MORE

Help Support Schizophrenia and Related Disorders Alliance of America
Amazon donates to Schizophrenia & Related Disorders Alliance. Shop for great deals at smile.amazon.com

Easy steps to support Schizophrenia and Related Disorders Alliance of America through Amazon Smile:

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

2. 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.

3. 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.

4. 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!!

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

I'm a new Text block ready for your content.

Help Change Lives -- Donate Now

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

Donate to SARDAA

Sincerely,
Angel White, Editor