Message from SARDA, CEO

Dear Friends,

Holidays bring a season of mixed messages and mixed feelings. We need to keep remembering that the most important gifts are the gifts that we don’t purchase but the gifts of time, caring and compassion. It is often a time of many challenges, especially for people who have losses, loved ones...
who are hospitalized or incarcerated, homeless or missing. We each must reach out to all who are struggling each and every day of the year. Refrain from accepting the stressors and pressures others, society and we ourselves present such as spending more than we can afford, taking more of our time than we have, doing more than is comfortable. Above all, be kind to yourself and others.

It's hard to believe that the year is coming to a conclusion so quickly, but we have much to reflect on and share. Please view some of the initiatives SARDAA has been leading.

- Our recent "Brains on Broadway" Symposium and Reception in NYC exceeded our expectations. As you know, we have built a broad coalition of people working together to change the treatment paradigm for people affected by psychosis brain syndromes. Based upon the very strong feedback from attendees and our panelists, we are actively planning a follow-on event in March to continue this important dialogue with additional families and stakeholders. I will share additional details over the next few weeks.

- SARDAA's Reclassification framework was referenced within the House of Representatives Energy and Commerce Committee budgeting process. Chairman Walden referenced my official statement within budget mark-up activities. He talked about the increasing need for better treatments for psychiatric conditions and the advances in better understanding in the underlying biology. He then went on to say that he agrees with SARDAA, and called us out by name, and included our talking points regarding serious concerns about future access to innovative therapies.

- I was invited by the White House's Domestic Policy Council lead staff to meet discuss SARDAA's work and mental health policies. Our meeting was very encouraging and Steve Wagner, Deputy Director of the Domestic Policy Council at the White House and Leslie Ford, Special Assistant to the President for Domestic Policy Domestic Policy Council shared that we provided them with new information. Please read the talking points here.

- Our formation of Chapters is continuing to go well in support of our goal to build a grass-roots support and service delivery network across the country. In less than one year, state chapter leads have been identified in 12 states and several additional interested leaders are organizing.

On December 19, 2019 our CEO Linda Stalters and Board Member Dr. Tim Murphy will represent you at the White House Summit on Transforming Mental Health Treatment to Combat Homelessness, Violence & Substance Abuse.

We welcome Robert Moran, Angela Babaev and Kurt Talbot who joined our amazing hardworking, dedicated, knowledgeable and passionate Board of Directors. Congratulations to the newly elected officers: Susan Sheena, Chair; Raymond Cho, Vice Chair; Mary Palafox, Secretary; Russell Stalters, Treasurer. Our other Board Members are: Sandy Dimiterchik, Robert Laitman, Tim Murphy, Laura Pogliano. Thank you to our great leaders who volunteer their time, expertise and treasure to change the paradigm and improve and save lives affected by psychosis brain illnesses.

Thank you for standing with us as we work toward these goals.

Thank you for being you,

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

'This isn't the life I ordered'...a thought in common by some people, possibly many, for various circumstances. 'That which one resists, persists'...so that ISN'T the way forward. I've read in some of my sources, and believe, that focusing on and practicing gratitude daily is a positive address of those concerns in life which otherwise might bring us down. It might not change the way things are, but it affects the way we perceive...very important. If we 'seek' positives, I can say from my experience, that it makes for better days. One sense of gratitude for me right now is to be in the holiday spirit and search those things which enhance this. I wish all in the SARDAA/Families for Care community a holiday which leaves one feel peaceful and uplifted.

In Heart,
Mary Ross
Message from SA Staff Supporter

Announcing SARDAA's New Facebook Group: SARDAA SA Support (Diagnosed)

By Sandy Dimiterchik
SA Staff Supporter

Here at SARDAA we have started a new Facebook group: SARDAA SA Support (Diagnosed).

Here is the link: 
Facebook SARDAA Support Group

Another way to get there is to do a general search for SARDAA, then scroll down until you find SARDAA SA Support (Diagnosed).

This group is only for people diagnosed with schizophrenia or related disorders, including bipolar disorder, schizoaffective disorder, depression with psychosis, or experience with psychosis.

To become a member, you must answer the question of whether you are diagnosed. We put this question in to ensure that members have a related diagnosis. This is a safe place for people who are diagnosed to discuss their illness and other things like recovery and stigma.

If you do not have a diagnosis, join or continue to be a member at the blended group (for diagnosed, family members, friends, advocates, etc.) at SARDAA Support.

If you have any questions, contact the office at info@sardaa.org or 240-423-9432
SARDAA needs volunteers!

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

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

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**Personal Story of SA Members**

**Krisztian K**

I am 32 years old. I must say I was very inattentive and absent-minded even in my childhood. I think this was because of the early effects of my disease. I was withdrawn and very shy. I think that’s why my classmates in the primary school often teased me and hurt me. My father humiliated me many times, too, he terrorized me the same way as his own father treated him. Both are alcoholics. In the school, my classmates often bullied and pushed me, just like my father did so at home. I didn’t dare stand up for myself, I was afraid that my situation would be worse. Later in high school at home I was able to protect myself because of workouts in karate and the weight training.

Hallucinations began when I was 19. I studied computer science. I often played computer games, didn’t work much, six times a week I spent 1-2 hours in the gym with my friends. I couldn’t learn. I could hardly concentrate during the lessons, I felt low though I didn’t know why and my thoughts were undisciplined. It has been so since I was 15.

I failed several times for these reasons. Then I started to hallucinate. I thought I was hearing only the neighbors’ voice as we lived in a terraced house and all the loud voices were audible. I wasn’t able to sleep for months, so I thought I was hallucinating because of the fatigue. I trusted it would go away by the next day. Unfortunately I continued to hear voices on the following days, steadily and more and more intensively.

I didn’t know what to do. I started a course of treatment with medical herbs but it didn’t prove good. I had been trying for months before I got to a psychiatrist. I told him what had happened. We performed a test and he said I was a schizophrenic. I didn’t want to believe it and I didn’t take the
Years went on before I was taken to a mental hospital. After the divorce of my parents, I went to live in another village with my mother and sisters.

After a year in my new place I was psychotic again. I don't remember everything exactly, but I remember that I didn't talk, didn't eat, didn't sleep OK, and didn't leave the house. Then the ambulance crew came and somehow they took me to the mental hospital. I spent months there before I could go home. I didn't take medicine systematically, I relapsed several times before I accepted that I was ill and I have to take medicine regularly, every day.

Since then I feel much better. I didn't finish the high school. I live with my mother, little sister and the second husband of my mother. If there is something my mother or my stepfather ask me to do, I help: I mow the lawn, I help in the kitchen garden, I put together spare parts of vacuum-cleaners my mother brings home from the factory where she works. I make some money this way. When winter comes, I help my stepfather cut trees in the wood nearby.

The rest of the lot of time I have I participate in my hobbies: I weight-train, learn to play the guitar, go to religious education, watch series. In the future I would like to have a permanent job, to live independently. I would like to learn to play the guitar, maybe the ocarina, too, to pass a language exam and to learn computer science as an autodidact. These are my aims.

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**A Book Review of *Shrinks: The Untold Story of Psychiatry* by Jeffrey Lieberman and Ogi Ogas**

By Sandy Dimiterchik, SA Staff Supporter

Back in the 1990s, when I was in Williamsburg, Virginia, over the winter holiday, there was an exhibit of the history of restraining mechanisms for the mentally ill. This was around the time I was becoming symptomatic, and I remember thinking to myself, at least I will never experience that. I had the same thought reading this book - thank goodness things are different now.

The cliché that you have to know where you were to really see the benefits of where you are now, could be applied to the experience of reading this book. It is amazing, and horrifying, to see what some people had to go through. I also was surprised to see the impact one person had on the field of psychiatry, like Sigmund Freud. I shouldn't have been surprised, remembering the change in society's view of the mentally ill in asylums by Dorothea Dix.

This book is not just about psychiatry, but also the entire field of mental health and all who are involved. Social media is also discussed, especially its impact on the DSM - 5 being approved. Legislation is mentioned, concerning HIPAA and the Helping Families in Mental Health Crisis Act. Nonprofits in the mental health field are described.

The book ends with a discussion of stigma. This is an important chapter, as everyone knows that no matter the high quality services that are available, it means nothing if not utilized. Also, there is a message of hope for what is to come. I agree with that feeling of hope. The book is well written, and I recommend this book to SA members and it would be a good book to discuss in SA groups.

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- David G.
**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?

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!

Thank you, Laura Pogliano

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**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
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 SARDAAN**

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. SARDAAN 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

After the item sells and the buyer pays, ship the item. The donation is not collected immediately to ensure the transaction is complete. In approximately 21 days, PayPal Giving Fund automatically collects the donation from the seller and sends a confirmation email.

PAYPAL GIVING FUND

At the end of each month, PayPal Giving Fund combines the donations from individual sellers and sends 100% to the selected charity.

For more details:
https://charity.ebay.com/help/seller

For more information visit: eBay for Charity

Reclassifying Schizophrenia - A Conference
David Geiger
November 11, 2019
This past November 4, 2019 SARDAA held a symposium in New York City regarding the reclassification of schizophrenia as a brain illness. Presently it is seen as a psychological/behavioral problem. Evidence was presented showing that it is a spectrum illness as much as cancer, autism, depression, and other similar disorders are spectrum illnesses.

READ MORE

ACADIA Pharmaceuticals Announces Positive Top-line Results from ADVANCE Trial of Pimavanserin as Treatment for Negative Symptoms of Schizophrenia
ACADIA to initiate second pivotal study in the first half of 2020
SAN DIEGO--(BUSINESS WIRE)--ACADIA Pharmaceuticals Inc. (Nasdaq: ACAD), today announced positive top-line results from its ADVANCE study, a 26-week, randomized, double-blind, placebo-controlled study in 403 patients. ADVANCE evaluated the efficacy and safety of adjunctive pimavanserin treatment in patients with predominantly negative symptoms of schizophrenia who have achieved adequate control of positive symptoms with their existing antipsychotic treatment. No drug is approved by the FDA for the treatment of the negative symptoms of schizophrenia.

READ MORE

Imaging Study Links Changes in Function and Structure of the Hippocampus in Early Psychosis
Brain & Behavior Research Foundation
Researchers have added an important piece to the scientific puzzle regarding one of the core features of psychosis. The new evidence is the product of advanced imaging that enables investigators to directly observe brain structure and function in living patients.

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Peer-Navigator Support for Latinx Patients with Serious Mental Illness
People who have a serious mental illness, or SMI, are at higher risk for other health problems. An SMI, such as depression or bipolar disorder, may make it hard for people to work or live on their own or to arrange for health care. These problems can be worse if language or cultural issues are barriers to receiving care.

In this study, the research team compared two types of care. The first type was integrated care. Integrated care includes both physical and mental health care at the same clinic. The second type was integrated care with a peer navigator. Peer navigators have backgrounds similar to patients and help patients find and use healthcare services. The team looked to see how well these two types of care worked to help Latinx patients with an SMI get the care they need.

READ MORE

RESEARCH WEEKLY: Shared Data Systems to Help Frequent Emergency Department Users with Mental Illness
Treatment Advocacy Center
Serious mental illness is a major contributor to emergency department crowding, as we highlighted in our latest evidence brief, Delayed and Deteriorating. In addition, frequent emergency department users, often a target of policymakers and hospital systems due to the high healthcare costs associated with their service utilization, often have mental health concerns that are unaddressed.

READ MORE

Rikers Island
The New York Times
Matthew Haag
November 23, 2019
According to Alisa Roth, a journalist and author of Insane: America’s Criminal Treatment of Mental Illness, Rikers Island in NYC is one of the three largest providers of mental health care in the country – and it is a jail. New York City voted to close Rikers by 2026.

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The Demons in My Head Road the Streets
Marcos Villatoro
November 26, 2019
The homeless population in this city has exploded. Tents are lined up and down Van Nuys Boulevard, near my home. People have set up living quarters behind some bushes at Walgreens, where I fill my prescriptions. During the day, most of the tents are empty. Maybe one person stays behind to watch over the camp, while the rest forage for food, money, recyclables and jobs. But some can’t work; they’re too busy battling their own minds.

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Glenn Close Started a Nationwide Conversation About Mental Illness
Ross Elliot, Media Planet
“My world changed,” actress Glenn Close says, “when my sister, Jessie, came up to me one summer day and said, ‘I need your help. I can’t stop thinking about killing myself.’” The award-winning actress had no experience talking about mental illness, despite a family history of depression,
alcoholism, and suicide. “We had absolutely no vocabulary for mental illness,” she says.

Why We Must Reclassify Schizophrenia Spectrum as a Neurological Brain Illness
Linda Stalties, M.S.N., Founder and CEO, Schizophrenia and Related Disorders Alliance of America

Reclassifying schizophrenia as a neurological brain illness will allow individuals with this disease to receive timely, appropriate care, and avoid criminalization and stigma.

The barbaric abuse and discrimination thrust upon individuals who suffer a neurological brain illness is horrific. We must start treating our loved ones, neighbors, and colleagues with schizophrenia appropriately, as we do for those with Alzheimer’s and Parkinson’s disease. Therefore, we should reclassify schizophrenia spectrum brain illnesses as neurological brain illnesses, and emphasize the fact that schizophrenia spectrum illnesses are childhood brain illnesses that cause progressive brain changes and require early treatment.

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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.

Shopping for the holidays?

When you shop at smile.amazon.com, Amazon donates.

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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Sincerely,
Angel White, Editor

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