Message from SARDAAN, CEO

Dear Friends,

November 4th was an amazing day. SARDAAN celebrated the opportunity to bring together brilliant enthusiastic people working together to change the treatment paradigm for people affected by psychosis brain syndromes. The speakers provided profoundly important education and direction. Our honorees displayed their extraordinary achievements bringing hope, heroism and role modeling to us all. Our Honorary Chair Glenn Close honored her nephew Calen Pick and his wife Megan with an especially compassionate and passionate tribute to them and all affected by these brain illnesses. Ms. Close created a beautiful video for the event that seemed anti-climactic to follow her talk so we present it here so everyone can benefit. Watch her video [HERE](#).

Ms. Close warmly and sincerely embraced guests and heard their stories. We shared one of the Bring Change 2 Mind videos that Calen selected and is one of my favorites; you can view it [HERE](#). Calen and Megan were presented the Dr. Frederick Frese Award by Dr. Penny Frese.

Paul Taylor’s musical artistry was spectacular - we could have listened to him all night long! Don't miss Paul Taylor when he performs near you [HERE](#).
We heard from everyone that we need to extend this movement and we are now working on Brains on the Beach in Hollywood, Florida, March 21, 2020 - you do not want to miss it!

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

Honor a Loved One and Double Your Gift
SARDAA has created “Tribute Funds,” an online network of fundraising created by donors who want to establish Tribute in honor or memory of someone with a serious neurological brain illness.

Even more exciting, an anonymous donor has graciously agreed to offer a Challenge Match Opportunity ($50 becomes $100) so that your donation will be automatically doubled! For easy instructions to create a Tribute Fund click HERE or if you prefer to simply donate now click HERE.

Message from FFC, Families for Care, Coordinator
On my life journey...in my role as care partner, the guidance on which I rely, that being 'to release attachment to outcome' relates to many aspects of life, including that which regards concern for my daughter. I am reminded to 'live in the now, as much as possible, to assess what is needed this day...this moment...what is helpful to her’? This helps to clarify for me that my role in her life is that of support, that making any changes is her role, her responsibility, her right to do or not. As with much in life there is a learning curve, but I believe that this thinking, this way, is key to life, to live in and seek what the moment holds.
In Heart,
Mary Ross

Message from SA Staff Supporter
Why support groups and pen pals help?
By Sandy Dimiterchik

According to NIMH or National Institute of Mental Health, 4.5% or 11.2 million adults have a serious brain disorder that disrupts people’s lives. However, NIMH statistics show that only 66% of those people receive treatment. As I myself know, the road to recovery can be long and lonely. At SARDAA, we try to help connect people with schizophrenia or related disorders, such as bipolar disorder, schizoaffective disorder, depression with psychosis, or experience with psychosis. That connection means making a friend or acquaintance with somebody who understands psychosis. As we say in the Blue Book, “We have these things and others in common. In a way, it’s like a homecoming. You are welcome here (Page 3, 2019 edition).

Joanne Verbanic herself knew of the difficulty of meeting people who understood the symptoms as she was diagnosed with schizophrenia. She said, “The stigma is harder to deal with than the illness itself (Page 26, 2019 edition)” There is discrimination against people who are diagnosed. Then, there are the symptoms that make it difficult to meet people, like paranoia or hallucinations. Back in 2013 when I found SARDAA and the SA conference calls, it helped me to start the journey of recovery. I remember reading in the Blue Book that recovery involved “the reduction and control of symptoms to the point of permitting one to have the ability to find and keep steady and structured activity (Page 24, 2019 edition). When I heard that, I thought, well that is something I can do, so I must be in recovery.

There are different ways to meet people through SARDAA. There are the SA or Schizophrenia Alliance: Psychosis Support and Acceptance support groups, the closed Facebook page called SARDAA Support, and now the pen pal program. For more information, contact me at sandy.dimiterchik@sardaa.org or call the main office at 240-423-9432.
The 2019 Walk for Mental Health Awareness in Houston was a success. The SARDAA Team raised $577.75 and SARDAA SA Staff Supporter, Sandy Dimiterchik, won a $50 gift card to HEB, a local grocery store chain. Volunteers Katie and Liz helped with answering questions from walk participants and the general public. The Walk itself raised $10,512.77 in total. Thanks again donors!

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

Personal Story of SA Members
Kira

I am 28 years old and I would like to share my story.

I used to be a really hard-working, persistent girl, full of ambitions: I wanted to exploit my gift at languages: English and German. So I
took an advanced level exam in English in order to be admitted to Anglistics at the University of Debrecen.

My daydream began after my 19th birthday. I thought everybody was talking about me as I showered in the bathroom. I was crying all night long and told my flatmate that all of her friends were telling lies and I said I was afraid of someone staring at me in the bathroom and I was alarmed that videos were being taken of me and everybody would see me online.

A year later I was taken to hospital by my parents, which was really degrading for me especially due to bad circumstances. I was sleeping a lot due to a huge amount of medicines.

One year later I tried to carry on university. However my illness returned and when my parents wanted me to attend another closer university in Budapest: I could not accept it and said it is not university and I became quite adversary against my family so I got back to hospital.

Finally I did not get degree at Anglistics, however I passed more exams at Tour guiding, Receptionist and shop assistant. I think life is a wise teacher and you can never learn enough to get stronger and stronger.

Later I got to know another man who seemed to be gentleman but later it became the deception of my life. He split up with me during a common holiday in Split at the Adriatic Sea.

After my 28th birthday suddenly I jumped out of the window of our detached house and I thought I will never return. However, thanks to the ambulance men, I was taken to hospital, got medicines and now I can tell you I can live with my illness and I can only hope I will be strong enough to cope with issues.

To sum up, I would like to say I am grateful for being the member of SA-group where we can share our problems, positive experiences with each other and it makes me feel better to find my place in the world.

Now I can admit I have made mistakes and accept the good influence of the medicines and I can trust my professionals and I believe in the common co-operation and I am convinced I can reach my goals through therapy and with attention. I think the first step to recover is possible if you take control of your illness in your own hands with help.
A Book Review of *On Conquering Schizophrenia* by Robert Francis
By Sandy Dimitchelik and another SA member, Gloria Q.

This book is an exquisite rendition of what it means for a person to experience and struggle with schizophrenia. The author, Robert Francis, draws on his personal experiences and education (undergraduate degree in philosophy and a Master’s Degree in Social Work) to explain and make sense of the illness. And overcome he does! By utilizing the philosophical doctrine of existentialism and his clinical background in social work (he is an LCSW). Francis negotiates the world of psychosis. This is definitely the thinking persons’ guide to conquering schizophrenia. To fully appreciate this book, one must be well educated and intelligent.

With his numerous religious experiences it is understandable that Francis would devote 8 of the 21 chapters to the question of the existence of God. This discussion in no way takes away from the importance of the book, for religiosity is often a function of psychosis; these God experiences feel very real when one is experiencing psychosis. But these God experiences are not the primary thrust of the book. Francis explains that he understands the illness existentially and that he holds this understanding in abeyance while he simultaneously considers his symptoms clinically and experientially: “I have become comfortable with perceptual ambiguity.” (p. 80). It is this exercise in mental dissection which allows him to function day-to-day. Through his twenty years of having the illness, Francis has
learned to identify psychosis when it is occurring and live with it. He has learned to recognize the symptoms and rather than being overcome by them, he has attained peace despite them. Later in the book he also mentions the importance of taking medication.

I would highly recommend this book to anyone who wants to gain insight into what it means to live with and experience psychosis, including SA and FFC members. While the author discusses the existence of God, he stresses that these are his own personal beliefs and that people can differ, in fact thrive, if their beliefs are different. This book gives a remarkable window into schizophrenia.

Robert’s book is available [HERE](#).

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**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

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 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.

SARDAA has chosen eBay for Charity so you can
directly support SARDA 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
   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
CMS Announces Approval of Groundbreaking Demonstration to Expand Access to Behavioral Health Treatment

November 6, 2019

Today the Centers for Medicare & Medicaid Services (CMS) announced the approval of a first-of-its-kind Medicaid demonstration project that broadens treatment services available to Medicaid beneficiaries living in the District of Columbia (“the District”) diagnosed with serious mental illness (SMI) and/or serious emotional disturbance (SED). At the same time, CMS is approving the District’s request to begin providing new services for its beneficiaries diagnosed with substance use disorder (SUD).

Smoking May Raise Psychosis, Depression Risk

Traditionally, it's been widely assumed that patients with mental illness start smoking to self-medicate, but a novel study suggests the reverse may be true — that cigarette smoking actually raises the risk of mental illness, including depression and psychosis. Investigators at the University of Bristol, United Kingdom, found that lifetime smoking and smoking initiation were both associated risk factors for schizophrenia as well as depression — an association that could, at least in part, be considered causal.

Are you interested in joining the 2020 Census team?

The Census Bureau is aiming to hire approximately 500,000 census takers in communities nationwide to help conduct the once-a-decade count.

After 60 Years, a Study Finds Children of Mothers with Bacterial Infections During Pregnancy Have elevated Psychosis Risk

Brain & Behavior Research Foundation

In a study that has been 60 years in the making, a team of doctors and scientists reports that bacterial infection during pregnancy significantly raises the risk that the offspring—especially male offspring—will have a disorder that includes psychotic symptoms. Schizophrenia is the most common illness that usually includes
psychosis, but psychosis is also seen in some cases of bipolar disorder and depression.

Alkermes Submits New Drug Application to U.S. Food and Drug Administration for ALKS 3831 for Treatment of Schizophrenia and Bipolar I Disorder
DUBLIN, Nov. 19, 2019 /PRNewswire/
Alkermes announced that it has submitted a New Drug Application (NDA) to the U.S. Food and Drug Administration (FDA) seeking approval of ALKS 3831 (olanzapine/samidorphan) for the treatment of schizophrenia and for the treatment of bipolar I disorder. ALKS 3831 is an investigational, novel, once-daily, oral atypical antipsychotic drug candidate designed to provide the efficacy of olanzapine while mitigating olanzapine-associated weight gain. The ALKS 3831 NDA includes data from the ENLIGHTEN clinical development program in patients with schizophrenia, as well as pharmacokinetic (PK) bridging data comparing ALKS 3831 and ZYPREXA® (olanzapine).

Biomarker for Schizophrenia can be Detected in Human Hair
Working with model mice, postmortem human brains, and people with schizophrenia, researchers at the RIKEN Center for Brain Science in Japan have discovered that a subtype of schizophrenia is related to abnormally high levels hydrogen sulfide in the brain. Experiments showed that this abnormality likely results from a DNA-modifying reaction during development that lasts throughout life. In addition to providing a new direction for research into drug therapies, higher-than-normal levels of the hydrogen sulfide-producing enzyme can act as biomarker for this type of schizophrenia.

Cost-Sharing Disparities for Out-of-Network Care for Adults with Behavioral Health Conditions
OBJECTIVE To evaluate the cost-sharing payments for out-of-network (OON) care for private insurance plan enrollees with mental health conditions, alcohol use disorders, or drug use disorders compared with those with congestive heart failure (CHF) or diabetes.

Delayed and Deteriorating: Serious Mental Illness and Psychiatric Boarding in Emergency Departments
Treatment Advocacy Center
November 2019
The number and proportion of mental health crisis emergency department visits have been steadily increasing in the United States in recent years. In 2014, there were more than 2.2 million emergency
department visits by patients whose primary diagnosis was serious mental illness. And as a result of a multitude of factors and failures in our mental health care system, instead of receiving timely and effective treatment, individuals are boarded in the emergency department, waiting for days or sometimes weeks, with nowhere to go and sometimes no treatment.

"Game-changing" New Schizophrenia Drug Passes Phase 2 Human Trials
Rich Haridy
November 18, 2019
A new drug designed to treat acute psychosis in schizophrenic patients is reporting impressively positive results from a Phase 2 clinical trial. After several decades of challenging development, the drug is hoped to be one of the most novel schizophrenia treatments to reach the market in years.

Genetic Data Can Improve Psychosis Prediction Tool
American Psychiatric Association
Incorporating genetic data into a clinical tool that predicts whether a person will develop schizophrenia can improve the accuracy of this tool, according to a study appearing in AJP in Advance. Diana Perkins, M.D., M.P.H., of the University of North Carolina and colleagues assessed whether polygenic risk scores (PRS) could be used as part of a clinical assessment of schizophrenia risk. A PRS reflects how many individual genetic variants associated with schizophrenia a person has; the higher an individual’s PRS, the greater his or her genetic risk of developing schizophrenia. They looked at health data from 764 young adults (average age 18) considered at high risk for developing psychosis. These young adults were participants in the North American Prodrome Longitudinal Study (NAPLS 2). As part of the NAPLS 2, these individuals were prospectively followed for two years to identify traits that might help predict the onset of schizophrenia.

Many Women with Schizophrenia Do Not Receive Mammograms, Meta-Analysis Suggests
American Psychiatric Association
Women with schizophrenia are only half as likely as women in the general population to receive mammograms, reports a meta-analysis published in Psychiatric Services in Advance. “Lower screening rates could explain why women with schizophrenia and other serious mental illnesses are found to have more advanced breast cancer at time of diagnosis,” wrote Alison Hwong, M.D., Ph.D., and colleagues at the University of California, San Francisco. “Given the high
prevalence of breast cancer and the promising prognosis of breast cancer if detected early, mammography screening is a key first step in improving diagnosis and treatment for people living with schizophrenia.”

**Transcranial Direct Current Stimulation May Effectively Treat Negative Schizophrenia Symptoms**
American Psychiatric Association
Transcranial direct current stimulation (tDCS) appears to be an effective and safe add-on treatment for ameliorating negative symptoms in schizophrenia, such as loss of interest in everyday activities and emotional withdrawal, according to a study published yesterday in JAMA Psychiatry. This noninvasive therapy delivers weak, direct currents into the brain via electrodes placed on the scalp.

**Policy Updates**

**An Integrated View into Treatment Resistant Schizophrenia**
Treatment Advocacy Center
A number of people with schizophrenia do not respond to any antipsychotic medication, a condition known as treatment resistance. The exact percentage is unknown since definitions of treatment resistant schizophrenia (TRS) vary widely and people respond differently to antipsychotic medications. It is estimated that approximately 30% of patients with schizophrenia do not respond to dopamine-blocking antipsychotics and of those, only half find symptom relief by the only alternative medication, clozapine. As a result, those with TRS typically experience poorer clinical outcomes. However, recent research is beginning to unravel the biological basis for non-response and may assist in the development of effective medications for this population.

**Lady Gaga Reveals She Started DBT Therapy, Olanzapine After Having a Psychotic Break in New Interview**
Leah Groth, Elle
November 6, 2019
There’s no denying it: Lady gaga is a powerhouse. In the past few years, not only has she continued cranking out music, but she’s also received critical acclaim for her role as Ally in A Star is Born, and recently launched her makeup brand, Haus Laboratories. But now, pop star is opening up (to Oprah Winfrey, no less) about her struggles with mental and physical health—and she’s not holding anything back.
Schizophrenia Risk Gene Linked to Cognitive Deficits in Mice
NIMH
October 24, 2019
Researchers have discovered in mice how one of the few genes definitively linked to schizophrenia, called SETD1A, likely confers risk for the illness. Mice genetically engineered to lack a functioning version of the enzyme-coding gene showed abnormalities in working memory, mimicking those commonly seen in schizophrenia patients. Restoring the gene’s function corrected the working memory deficit. Counteracting the gene’s deficiencies also repaired neuronal circuit deficits in adult mice — suggesting clues for potential treatment strategies. A team of scientists led by Joseph Gogos, M.D., Ph.D., of Columbia University, New York City, reported on their research — supported by the National Institutes of Health — in Neuron.

Schizophrenia Memory Deficits Reversed in Adult Mice
Genetic Engineering & Biotechnology News
October 10, 2019
An international research team headed by scientists at Columbia University restored normal working memory in a mouse model of schizophrenia (SCZ). The achievement, demonstrated using both genetic, and pharmacological approaches, effectively reversed in adult mice a core symptom of the neuropsychiatric disorder that has proven almost impossible to treat in humans. The work also challenges the common assumption that cellular changes that underlie memory issues in schizophrenia cannot be repaired once symptoms have developed.

Find Clinical Trial Participation by State:  HERE

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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!!

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Shop with PayPal and choose SARDAA to Donate with PayPal Giving Fund to help support SARDAA.

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