Message from SARDA, CEO

Dear Friend,

September is an exciting time for starting a new school year, the beginning of Fall and for SARDA strategizing in grander detail how to reclassify schizophrenia and shift the treatment paradigm for people who are affected by the most serious neuropsychiatric illnesses.

We continue to focus on our goal to improve lives affected by the most serious neuropsychiatric diseases:
We have sent a letter to

Director Robert R. Redfield, MD
U.S. Centers for Disease Control and Prevention
1600 Clifton Road NE
Atlanta, GA 30329
Requesting the Inclusion of Schizophrenia in National Neurological Conditions Surveillance System (NNCSS)

We are working to collaborate with other stakeholder organizations to work together on how we can make REAL changes that matter the most (HIPAA, IMD Exclusion, AOT) to those who are living with psychosis and anosognosia.

We are offering the L.E.A.P. Train the Trainer Training in the Washington, DC area on February 7 – 9, 2019.

There are many more items on our agenda.

We will have some very exciting news in the coming weeks!

We can’t accomplish all these things without your help! Please donate NOW so we can work for the most seriously neuropsychiatrically ill.

Warmest regards,
Linda Stalters, MSN, APRN (ret)
Chief Executive Officer
Schizophrenia And Related Disorders Alliance of America
Grace Lee, a SARDAA staff member living with schizoaffective disorder, will be participating in The Walk for Mental Health Awareness--Houston to raise funds for our mission.
Support her 5K walk [HERE](#)

Message from FFS, Family and Friends, Coordinator

LEAP, is the support program of Xavier Amador, PhD for families and friends of those diagnosed with neurological brain disorders, and more specifically of help regarding those challenged with anosognosia, the lack of insight into one's illness. He authored the book 'I Am Not Sick, I Don't Need Help...How to Help Someone with Mental Illness Accept Treatment'. This program, based on trust and respect, may benefit both the families/friends and the one diagnosed, as it holds promise of facilitating positive communications and interactions between the parties. L refers to LISTEN; E to EMPATHIZE; A to AGREE (I also think 'align') and P to PARTNER. By learning the benefit of each of these guidelines we may see an improvement in the challenges and frustrations we encounter from BOTH perspectives. On this path as a care partner I am tuned to much incoming relevant information that upon hearing a radio
service announcement referring to a learning disability which said “when we see their side we can be on their side”, I related. ‘LISTEN’ the first, and possibly most important part of LEAP reminds me of a quote by Mark Nepo, that being “To listen is to lean in, softly, with a willingness to be changed by what we hear”. It is also expressed in a poem written years ago by members attending a Racine WI DCS conference. It follows:

“LISTEN”
>“When I ask you to listen to me and you start giving me advice, you have not done what I asked.
>When I ask you to listen to me and you begin to tell me that I shouldn't feel that way, you are trampling on my feeling.
>When I ask you to listen to me and you feel you have to do something to solve my problem, you have failed me, strange as that may seem.
>Listen! All that I asked was that you listen -not talk, or do- just hear me.
>Advice is cheap. Twenty cents will get you both Dear Abby and Billy Grahm in the same newspaper.
>All I can do is do for myself. I am not helpless -maybe discouraged, but not helpless.
>When you do something for me that I can and need to do for myself, you contribute to my fear and inadequacy.
>But when you accept as a simple fact that I do feel what I feel, no matter how irrational, then I can quit trying to convince you, and get about this business of understanding what is behind this irrational feeling.
>When that is clear, the answers are obvious, and I don't need advice. Irrational feelings make sense when we understand what's behind them.
>Perhaps that is why prayer works, sometimes, for some people - because God is mute, and he doesn't give advice or try to fix things. He just listens, and lets you work it out for yourself.
>So, please listen and just hear me. If you want to talk, wait a minute for your turn-and I'll listen to you”.

LEAP is extensively available on the Web via 'LEAP Xavier Amador' and it will take you to The LEAP Institute, among other related info. It is a worthwhile investment of time and interest, and the book, a valuable reference for your library. Even though I am aware of this valuable information, I still have much to learn.

With Heart,
Mary Ross

The Friend and Family, FFS phone support group is on Tuesdays at 7 pm ET. Given the time zone difference of three hours between East and West coasts it is challenging to meet everyone’s needs, so we would like to establishing a second group for the west coast callers. If you, or anyone you know, would be so committed to starting such a group please contact CEO Linda Stalters at linda.stalters@sardaa.org....much gratitude.
Message from SA Staff Supporter

SARDAA News

By Sandy Dimiterchik

Have you ever heard of RAISE? It stands for Recovery After an Initial Schizophrenia Episode. It consists of research and pilot projects started in 2008 through National Institute of Mental Health (NIMH) to determine the benefits of coordinated specialty care (CSC) for people with first episode psychosis (FEP). Psychosis is when a person becomes detached from reality, and can include hearing voices or seeing things. CSC consists of groups of professionals who assist with medication, counseling, coaching for work and/or education and peer support groups. The research showed that people were assisted through these programs.

There are numerous CSC programs found throughout the United States. SARDAA is currently developing a spreadsheet of all the FEP and/or Early Intervention of Psychosis (EIP) treatment centers so that we can provide this information as a resource on our sardaa.org website. Right now there are over 180 of these centers. The centers serve different age ranges, duration of psychosis, and county locations. That way the diagnosed individuals can be helped and will be able to set professional goals, depending on their own situation, through the treatment centers.

We also started a new weekly conference call, on Saturdays at 3 PM Eastern Time, called Adolescent or Early Adult SA Conference Call Group. We hope to reach people as early as possible who are experiencing psychosis. To participate, call 1-855-640-8271, and then enter passcode 88286491#. For more information call 240-423-9432.

Personal Story of SA Members

Scott
I came from a well-to-do family and was trained from early childhood to grow up and become a professional person of some sort. Everything seemed to indicate I would succeed in this endeavor as the years passed. I got excellent grades in school and was an excellent athlete. I did all the right things.

Somewhere around the age of 17 or 18, I noticed that I was not feeling quite right mentally. Things were confusing, not making any sense, and I started losing my sense of connectedness. To deal with this, I started drinking alcohol more and more. I was very lonely and unhappy. My parents and others tried to help me “snap out of it,” but to no avail. The year I entered college, I developed a serious drinking problem and, as I learned later, crossed over the line from social drinking to alcoholism. Maybe I crossed over earlier, I don’t know. But I tell you, being arrested for drunk driving several times and spending time in jail was no fun.

Anyway, I got sober by entering treatment and Alcoholics Anonymous about a year later. I was exhilarated, although things still didn’t seem to be quite right. I felt lost. About 14 months into my new life, I decided to find some meaning to my existence. While
on a trip with an acquaintance I noticed things were really quite different. The leaves in the wind seemed to be talking to me. Cloud formations had special meanings. Television and radio shows were talking about my life. And I thought I could read peoples’ minds and communicate with them without speaking. I thought I had found what great spiritual leaders termed “being spiritual.” I truly thought I had been blessed by God and that I had a direct pipeline to Him. I felt happy and scared at the same time. I was in a different world.

About one week later I decided to travel out to the West Coast to really find myself, given this new-found power. While traveling, it seemed like God’s voice entered into my thoughts and told me to do something if I wanted real peace and power in my life. That being, to run my car off the road and leave the rest to Him. I did this only to find no peace, but a totaled car and a trip to the state mental hospital.

Since that time, I’ve been dealing with a disease called schizophrenia. It has been an uphill struggle. At the time of this writing, I believe I’ve found a way to pull myself out of psychosis and feel connected like before the alcoholism and schizophrenia. Today I feel peace, own a thriving business and have a wonderful relationship with my wife. We’re in the process of planning a family. This has been accomplished by the philosophy of Schizophrenia Alliance, Alcoholics Anonymous, and a few special people in my life.
We welcome your message/art from SA Members for inclusion in the newsletter. Please submit your message to: info@sardaa.org or mail to SARDAA PO Box 941222, Houston, TX 77094-8222 for consideration for next month's newsletter.

Your story might be included in a SARDAA newsletter and might be published in a future edition of the SA Blue Book.
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

**Adolescent or Early Adult SA Conference Call Group**
Saturdays - 3 pm Eastern Time

**Spirit of SA Conference Call**
For SA Leaders and Potential Leaders
First Wednesday of Each Month - 7 pm Eastern Time

**Family and Friends Support Group**
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 Group**
Only for individuals diagnosed
JOIN The Facebook Group Here
“Disorganized Thinking” in Psychosis is Linked to Brain Processing Problem in Cerebellum
Brain & Behavior Research Foundation
Jessica Bernard, Ph.D.
August 13, 2018
Texas A&M University
New data gleaned from learning-task experiments and fMRI imaging of young adults at clinical high risk for psychosis support the theory that problems in a particular brain circuit contribute to the disorganized thinking seen in patients with
schizophrenia, according to a new report in the journal NeuroImage: Clinical.

The experiments allowed the research team to examine in detail a circuit in the cerebellum, at the base of the brain, while the circuit was active. They focused on the circuit’s role in producing “rules” and models during learning - procedures that make thinking efficient and powerful. The research was led by Jessica Bernard, Ph.D. of Texas A&M University, who received her 2014 Young Investigator grant as a Donald and Janet Boardman Investigator; the senior author was Vijay Mittal, Ph.D., a 2017 Independent Investigator at Northwestern University.

Higher Neutrophil Counts Associated With Brain Changes in First-Episode Psychosis
Medscape
By Reuters Staff
August 22, 2018
NEW YORK (Reuters Health) - Higher peripheral neutrophil counts are associated with reduced gray matter, enlarged ventricles and more severe symptomatology in patients with first-episode psychosis (FEP), researchers report.

There has been little interest in the possible role of peripheral immune cells in schizophrenia, because the blood-brain barrier (BBB) restricts their entrance into the brain. Under certain conditions, however, the BBB may be disrupted and allow peripheral blood cells to enter the brain.

Dr. Christian Stephan-Otto from Parc Sanitari Sant Joan de Deu, in Barcelona, Spain, and colleagues investigated differences in brain volume and blood cell counts in 137 FEP patients and 81 healthy controls.

Risk of Agranulocytosis for Patients on Clozapine May Be Overstated, Study Shows
American Psychiatric Association
Neutropenia appears to be common both in patients with schizophrenia who are taking clozapine as well as those who have never used clozapine. Moreover, progression from mild neutropenia (1500-1900/mm3) to agranulocytosis appears to be rare, according to a report in BMC Psychiatry.

The results suggest that the risk of agranulocytosis associated with clozapine may be overstated. They also appear to lend support to the 2015 decision by the Food and Drug Administration to lower the neutrophil count cutoff at which patients are required to discontinue Clozaril from 1500/mm3 to 1000/mm3.

Schizophrenia Patients Show Cognitive Improvements After Smoking Cessation
American Psychiatric Association
Quitting cigarette smoking may improve processing speed in patients with schizophrenia, according to a study in AJP in Advance. Smoking is highly prevalent among people with schizophrenia, and these findings add another reason to encourage smoking cessation in this population, noted study authors Jentien Vermeulen, M.D., of the Amsterdam Institute for Addiction Research and colleagues.

Vermeulen and colleagues analyzed data from a study that included 1,094 patients with nonaffective psychosis, 1,047 patient siblings
without psychosis, and 579 control subjects. As part of this study, participants took part in cognitive tests at baseline and then three and six years after enrollment. Complete cognitive data was available for 916 patients, 947 siblings, and 552 controls.

**Survey**
Would you consider genetic counseling for your personal and/or family history of neuropsychiatric or mental health problems?

**White House Press Release**
July 25, 2018
Proclamation, Anniversary of the Americans with Disabilities Act, 2018
By the President of the United States of America

**Behind Bars, Mentally Ill Inmates Are Often Punished For Their Symptoms**
July 10, 2018
Dave Davies
By some accounts, nearly half of America's incarcerated population is mentally ill — and journalist Alisa Roth argues that most aren’t getting the treatment they need. Roth has visited jails in New York, Chicago, Los Angeles and Atlanta and a rural women's prison in Oklahoma to assess the condition of mentally ill prisoners. She says correctional officers are on the "front lines" of mental health treatment — despite the fact that they lack clinical training. "Most of the correctional officers will talk about how this is not what they signed up," Roth says. "Most of them have not had much training in dealing with mental illness — or they’ve had none at all."

**Treatment Advocacy Center** provides comparisons between Assisted Outpatient Treatment versus Mental Health Courts, [here](#); homelessness among veterans with serious mental illness, [here](#); whether the use of anti-psychotic medications and the presence of a security officer may prevent needing to resort to seclusion and restraint in inpatient psychiatric hospital settings, [here](#); and fascinating new research indicating that nitrates - chemicals used to cure meats such as in beef jerky, hot dogs, and other processed meats - may contribute to mania, [here](#).

[Donate to SARDAA](#)

![Schizophrenia](#)
Brain Campaign:

*Take the Pledge*

**I will** change my language from Behavioral or Mental disorder to Brain disease.

**I will** educate others to change their language from mental illnesses to brain illness.

**I will not** use stigmatizing, discriminatory or derogatory language related to brain diseases.

**I will** encourage my peers, family members, and colleagues to advocate when they see discriminatory language or practices in the media or in public.

**I will** advocate that people with brain diseases have equal and comprehensive health care.

**I will** treat all people with brain diseases with respect and compassion.

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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!!

**IT'S SO SIMPLE: just bookmark this link** [http://smile.amazon.com/ch/33-1213657, start shopping and support us every time you shop.](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 **90425**

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**Help Change Lives -- Donate Now**

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

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**Sincerely,**
Jordan Helwig, Creative Designer
Angel White, Editor