

## Newsletter

August 2017



# SARDAA

Shattering Stigma – Realizing Recovery  
Schizophrenia and Related Disorders Alliance of America



### Message from SARDAA, CEO

Dear Friends,

Summer is definitely here and more than the weather has heated up. SARDAA is focusing on what will truly make a difference in the treatment for people affected by serious neuropsychiatric illnesses. Al Guida is guiding our efforts to move schizophrenia into the appropriate classification as a neurological disorder. This move will inform everyone that schizophrenia spectrum disorders are not elected any more than Alzheimer's or Parkinson's diseases, therefore people require treatment not incarceration or homelessness.

We are planning a 2018 scientific conference in Houston that will focus on the scientific evidence of schizophrenia spectrum disorders and treatments available as well as a Schizophrenia Alliance and

Family and Friends Support Groups workshop.

There is so much to do and in order to accomplish what is important to you and your loved one(s), we need your help. Funding is required for experts to research and guide us, travel to the legislators to rally sponsors for what we need to do and dedicated volunteers are needed to organize our efforts and support our groups.

We welcome Flora Davis, M.A, CFRE to the SARDAA team. Flora is our Director of External Affairs and will help move us forward in our efforts to improve lives affected by schizophrenia related brain disorders. Flora is an agent of change development executive with more than 20 years of experience in planning, directing and implementing comprehensive development programs based on industry best practice standards. Known for encouraging others to reach higher and remain motivated to achieve goals. Seen as a collaborative servant leader with the ability to work with diverse groups of people, remain calm under stressful situations, problem solve challenging situations, monitor and drive for results based upon strategic performance measures.

Hope you have visited the new SARDAA website. While it is amazing, we continue to make changes to update and improve the content. Adit has created our new website and we are grateful for the many volunteer hours they have contributed to make this bold change.

Please know that SARDAA is THE national organization that is fully focused on improving lives affected by the most serious neuro-psychiatric illnesses.

Warmest regards,  
Linda Stalters, MSN  
CEO  
Schizophrenia And Related Disorders Alliance of America

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We welcome our two newest board members  
JD Garnier and Dr. Raymond Cho



**JD Garnier**, is a Private Client Advisor for US Trust, Bank of America Private Wealth Management, where he leads a team of advisors in managing assets for families. He has over 17 years of experience in the financial service industry and has a focus on estate planning, tax planning and investment management for business owners. J.D. attended Loyola University and received a Bachelors in Business Administration. He received a law degree from South Texas

College of Law and is licensed with the Texas Bar Association. J.D. is also Certified Financial Planner (CFP®). J.D. is a committed volunteer in multiple community organizations.



**Raymond Young-Jin Cho MD**, is an Associate Professor of Psychiatry at the UT Health Science Center at The Houston Department of Psychiatry and Behavioral Sciences in Houston, Texas. Dr. Cho embody the spirit of the community and brings talent and expertise and energy to the table. We are very fortunate to have him by our side as we continue to promote improvement in lives affected by schizophrenia-related brain illnesses (mental illnesses involving psychosis).

Dr. Cho currently is actively involved with the Society for Neuroscience, Organization for Human Brain Mapping, Cognitive Neuroscience Society, Society of Biological Psychiatry and the American College of Neuropsychopharmacology.

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## SAVE THE DATE!

*Shatter Stigma*  
Thursday, October, 2017  
6:30 - 10:30 PM  
New York City  
Watch for details  
Lydiane Interdonato, Chair

*Help improve lives affected by schizophrenia-related brain disorders*

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The voice they want  
to hear is **yours.**

### Message from FFS, Family and Friends, Coordinator

Having just attended a performance by singer/songwriter 'Celia', I wish to revisit the following 2015 message which highlights



'caregiving'. Celia created this from her heart, knowing of the adversity in our special lives.

So, here we are, SARDAA Family and Friends, with a lot in life we hardly anticipated; a lot that brings challenges, but less than that faced by our loved ones with a diagnosis. Very likely they have awareness of how their illness impacts our lives, but not always expressed. This expression may be found in the lyrics of 'The Caregiver's Song' by singer and songwriter Celia Farran. Celia's heart 'for all things right' is heard in her song, with which you may identify. I do.

### **The Caregiver's Song:**

I wouldn't wish it on anyone.  
The roller coaster you've been on with me.  
And for the times I'm not easy.  
I am sorry.  
There's a blessing in heartache.  
There is love beyond pain.  
I take nothing for granted.  
And I'll never be the same.  
Thank You.

Chorus:

For Caring for me.  
You are my family.  
It's not easy feeling broken.  
But I want the world to see.  
How you have cared for me.

[READ MORE LYRICS AND HEAR IT HERE](#)

The melody is as stirring.

With heart,  
Mary Ross

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### **From the Desk of John P. "Happiness Series"**

Personal Control and Happiness. An ABC-News special considers as one of the five key factors leading to more happiness the level of "personal control" a person has over his or her life. This resembles something called Control Theory, which distinguishes between an internal locus of control and an external locus of control. An "internal locus of control" is a person's belief that life outcomes are largely the result of one's own attributes and behaviors. On the other hand, an "external locus of control" is the belief that outcomes are largely determined by factors and forces outside of one's control. Some research shows that people with an external locus of control are more susceptible to depression, learned helplessness, a sense of victimization, and negative responses to aversive stimuli. On the other hand, people with an internal locus of control appear to be happier.

[READ MORE](#)

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## **60 Tips to Cope with Serious Neuro-Psychiatric Illness in the Family**

by Rex Dickens, Submitted by DJ Jaffe

If you have a family member with a serious neuro-psychiatric illness, remember these points:

1. You cannot cure a neuro-psychiatric disorder for a family member.
2. Despite your efforts, symptoms may get worse, or may improve.
3. If you feel much resentment, you are giving too much.
4. It is as hard for the individual to accept the disorder as it is for other family members.
5. Acceptance of the disorder by all concerned may be helpful, but not necessary.
6. A delusion will not go away by reasoning and therefore needs no discussion.
7. You may learn something about yourself as you learn about a family member's neuro-psychiatric disorder.

[READ MORE](#)

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We welcome your message/art from SA Members for inclusion in the newsletter. *Please submit your message to: [info@sardaa.org](mailto: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.*

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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

#### **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](#)

*This is a Closed group, ask to be added.*

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**\*\*\* HOW TO START AND GROW A SA GROUP \*\*\***

By Margery Wakefield

Welcome to SA (Schizophrenics Alliance)! I understand that you want to start an SA group, and that is great! [READ MORE](#)

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*Volunteer  
Opportunity!*

Schizophrenia Alliance  
Support Group Leader to  
Lead SA Support  
Group Conference Calls on  
Saturdays.

Please contact Angel 240-423-9432 for  
more information.

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**Help for people with Schizophrenia and Related  
Disorders.**

Now it is easy to record details and specifics about symptoms, medication, moods, and more. Choose what you want to track, and see all the information you need to help you or your loved one who is living with schizophrenia and related disorders.

**Get the Schizophrenia Health Storylines™ Mobile App Today!** The mobile app is FREE for all users on iOS and Android devices. There is also a web version available, accessible through the browser of any desktop computer or mobile device.



SARDAA and Self Care Catalysts had the opportunity to work with Kristy Speaks, an individual, like you, living with schizophrenia. Kristy is a mother of 3, who after graduating from nursing school, was diagnosed with schizophrenia.

She said that out of all the apps in the market, Schizophrenia Health Storylines self-care app was the most supportive as it allows her to track her symptoms, moods and journal her thoughts. In addition, Kristy designed a Positive Affirmation tool that launched at the end of March!

To show your support for Kristy, we are reaching out to you to [download the app](#) today! We hope that you benefit the same way she does!

[Download](#) Schizophrenia Health Storylines today!

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1. **Do you want to contribute to a short story anthology?**
  2. With the help of staff at Johns Hopkins University, I am compiling a short story anthology that will exclusively feature short stories written by people with disabilities. All of the stories will feature disabled main characters.
  3. [FIND OUT MORE](#)
  4. Emily Dorffer, disabilitysubmissions@gmail.com, 281-734-7370

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***Submitted by:***  
***Larry Ackerman/Sparrow Sang Blues***  
Author, Singer-songwriter,  
...the "Artist who Plays Guitar..."

*"...There falls into each life, a given amount of suffering, such that, if we are true to it, it deepens us where we stand."  
[from: Canticles of Desperation, a novel]*

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### **Parity Complaint Registry for mental health and addiction coverage**

The Parity Complaint Registry has been launched to create a national registry which will be used to track, study and report on how insurance companies are making adverse determinations. This information will help us work for better mental health and addiction coverage. <https://parityquest.org/>

\*Please note: this registry does not automate the appeals process. The Complaint Registry records and documents your complaint which will help provide the needed information to help shape public policy and influence legislation. **You must take follow-up action with your health plan or regulatory agency. The [Resources Page](#) can provide you with helpful information.** Click here for some [parity violation examples](#). Click here to [Register a complaint](#)

### **NICHD scientists uncover role of proteins in neuron activity and neurological disease**

June 23, 2017

Brain proteins known as neuregulins are important for establishing normal brain activity, according to recent studies led by researchers at the National Institutes of Health. Genetic changes in neuregulins are thought to increase the risk of schizophrenia, but it is not understood how such changes might increase the risk for the disorder.

[READ MORE](#)

### **How physical exercise prevents dementia**

July 21, 2017

Numerous studies have shown that physical exercise seems beneficial in the prevention of cognitive impairment and dementia in old age. Now researchers at Goethe University Frankfurt have explored in one of the first studies worldwide how exercise affects brain metabolism.

[READ MORE](#)

### **Electrical Stimulation of Brain May Help People with Schizophrenia Learn to Communicate Better**

July 16, 2017

UCLA researchers have found that people with schizophrenia were able to more accurately determine whether two auditory tones matched or differed, after receiving a type of electrical brain stimulation. Being able to distinguish tones is essential for verbal communication.

[READ MORE](#)

### **A noninvasive deep brain stimulation technique**

June 13, 2017

Brain stimulation therapies can play a role in treating certain neuro-psychiatric disorders. The approaches involve activating or inhibiting brain activity using electricity. Deep brain stimulation was first developed as a treatment for Parkinson's disease and subsequently used to treat epilepsy.

[READ MORE](#)

### **Form to request documentation from an employer-sponsored health plan or an insurer concerning treatment limitations**

This is a tool to help you request information from your employer-sponsored health plan or your insurer regarding limitations that may affect your neuro-psychiatric health or substance use disorder benefits.

[READ MORE](#)

### **FAQs about neuro-psychiatric and substance use disorder parity implementation and the 21<sup>st</sup> Century Cures Act part 38**

June 16, 2017

Set out below is an additional frequently asked question (FAQ) regarding the implementation of the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA), as amended by the Affordable Care Act and the 21st Century Cures Act (Cures Act).

[READ MORE](#)

### **Webinar: The Role of Community and Family Supports in Helping People Improve Their Complex Health Conditions**

August 2, 2017, 1:00-2:00 PM ET

This SAMHSA Recovery to Practice webinar will draw from the

practical experience of the presenters to explore the importance of the intentional family - those who support our wellness; discuss how community membership and natural supports impact health outcomes and the process of recovery; identify innovative ways to integrate social, family, and community resources to support the needs of both the person and the family; and discuss the whole family approach to services and supports.

[REGISTER HERE](#)

### **Webinar: The Role of Family Caregiving in Chronic Illness: Three Studies**

August 9, 2017, 3:00-4:00 PM ET

This VA webinar will summarize findings from three studies, including the roles, motivations, and barriers to engaging family caregivers in the chronic illness self-management from the perspectives of patients, family caregivers, and clinical providers. The presentation will also review a pilot intervention study intended to improve collaboration and communication between patients and family caregivers to enhance self-management.

[REGISTER HERE](#)

### **SAMHSA's 2017 Voice Awards**

August 16, 2017, 7:30 PM PT, Los Angeles, CA

SAMHSA's 2017 Voice Awards honor people in recovery and their family members who are community champions seeking to improve the lives of people with mental illnesses and addictions. The Voice Awards also recognizes television and film productions that educate the public about behavioral health and showcase that recovery is real and possible. This year, the Voice Awards is putting the spotlight on individuals and entertainment productions that provide hope and support to those past and present service members who have faced mental health and addiction challenges. Reserve your seat (whether in person or online) no later than Friday, August 4.

[READ MORE](#)

### **Webinar: Mental Health Economics: Analyzing Value**

August 22, 2017, 9:00-10:30 AM ET

This NIMH Global Mental Health webinar is aimed primarily at researchers and health care practitioners interested in addressing or better understanding issues of cost, cost-effectiveness and value in their work. There is an increasing expectation and need to demonstrate not only the health and other impacts of interventions and innovations in health, but also assess what it takes in terms of resources to develop, maintain or scale-up an intervention, and be able to link resources and costs to primary outcomes of interest. Accordingly, the webinar will start with an overview of key principles of health economic analysis, before moving into a presentation of analytical steps, methods and data

requirements. Participants should come away with a better grasp of why economic analysis is needed, what is required to do it and how to go about it.

[REGISTER HERE](#)

### **Virtual Event: Annual Summit: Advances in the State of the Science and Best Practice**

September 19-21, 2017

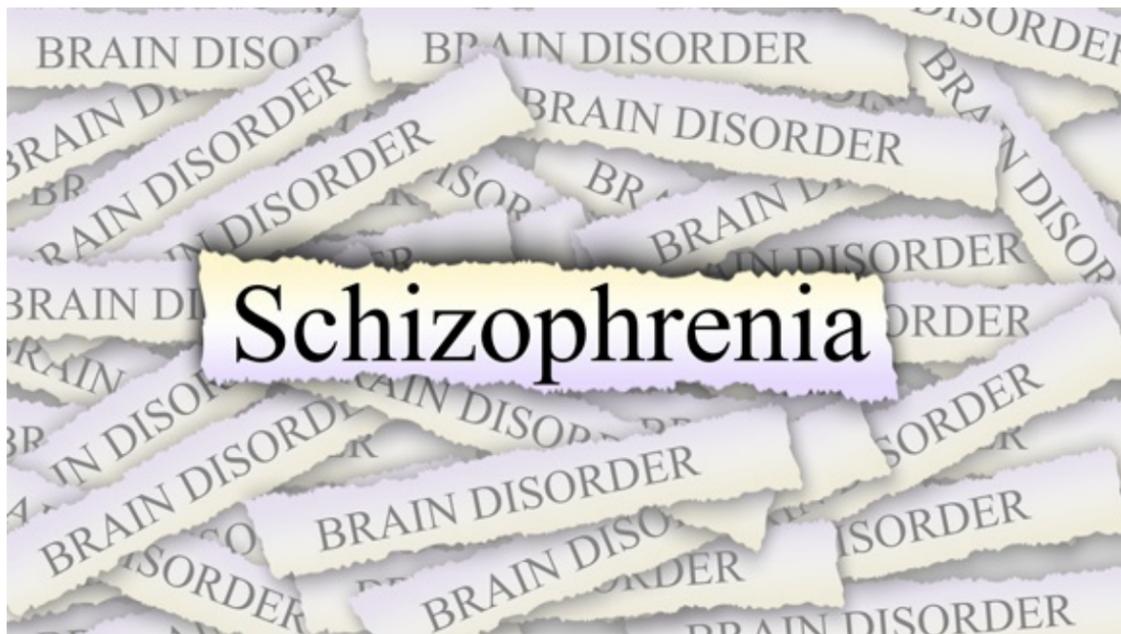
The 2017 Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury Annual Summit will connect health care professionals, researchers, and academicians involved in all aspects of psychological health and traumatic brain injury care for the military community. This year's event will offer real-time access to up to 28 hours of state-of-the-science programming. Join others from around the globe to participate in panel discussions and question and answer sessions, network with professionals and peers, visit the virtual exhibit hall for resources, and earn up to 14 CECs during the virtual event.

[REGISTER HERE](#)

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[Donate to SARDA](#)

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Brain Campaign:

**[Take the Pledge](#)**

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

**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 disorders.

**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 disorders have equal and comprehensive health care.

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

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### **Help Support Schizophrenia and Related Disorders Alliance of America**

Amazon donates to Schizophrenia & Related Disorders Alliance. Shop for great deals at [smile.amazon.com/ch/33-1213657](http://smile.amazon.com/ch/33-1213657)

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

Sign in to your Amazon account at [smile.amazon.com](http://smile.amazon.com).

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.

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.

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](http://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.***

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



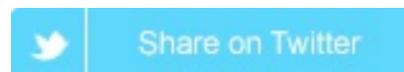
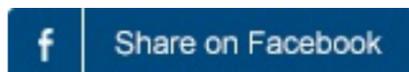
You can support SARDAA without spending a penny! Register Schizophrenia and Related Disorders on your Kroger Plus Card and they will donate a percentage to SARDAA each time you use your card.

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.



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

