Message from SARDA, CEO

Dear Friends,

As we approach another holiday season many people experience different reactions. Many approach this time of year with joy and excitement. Others might approach with uncertainty, dread and sadness. Many have unrealistic expectations that lead to frustration, disappointment, sadness and triggering of symptoms. Please read below for some brief but important things to keep in mind as we enter this stressful time of year.
Holidays are especially difficult for people who are so seriously ill that they are unaware they are ill and remain untreated, thus they continue to suffer with psychosis, and might be incarcerated or homeless. Their loved ones are suffering as well. WE MUST and will change this paradigm! People with brain illnesses must be given the opportunity for treatment.

We must urge the FDA to be more realistic in the way clinical trials are performed and validated so that each person has an opportunity to receive the medication that will specifically help them live a meaningful life.

I am personally grateful for the many truly wonderful people I work with and serve. I have the opportunity to know some of the most amazing people who are kind, altruistic, successful and working hard to change the world!

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

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Nonprofit Executive Joins SARDAA to Lead Operations and Accelerate Growth

SARDA is proud to announce the addition of our very accomplished Executive Vice President Gordon Lavigne. Gordon’s extensive nonprofit management and fundraising experience will help propel SARDA’s next phase of growth. His operations and fundraising experience over the past 17 years have helped transform nonprofits from small regional charities into leading international organizations. Gordon has worked with the Alzheimer’s Association, Autism Society of America, UC Berkeley’s Alumni Association, the ALS Association, Rebuilding Together, and the Grameen Foundation.

An enthusiastic welcome to Executive VP, Gordon Lavigne.

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SARDAA Announces Transformational Agenda in Support of Those Living with Serious Brain Illnesses Launches Year 1 of Action

SARDAA is taking bold steps. There has never been a more urgent time for you to stand Up and Stand with us as we aim to transform the treatment paradigm for schizophrenia spectrum illnesses.

Our medical experts tell us that we have never been closer to making disease-modifying progress in the fight against schizophrenia spectrum brain illnesses. BUT we know that too many people are exhibiting the signs and symptoms of serous brain illness and are undiagnosed and untreated. And we know that earlier and more consistent quality of care for people experiencing signs
and symptoms are desperately needed even for those with anosognosia.

**ACT NOW** in support of the following major initiatives:
- **CREATE** robust network of nationwide volunteer-led Chapters [VOLUNTEER HERE]
- **PROVIDE** educational support groups, services locator, and trainings for those affected (diagnosed and family) by serious brain illness [SUPPORT GROUPS HERE]
- **SUPPORT** our partnership nationwide expansion and rollout of the L.E.A.P. interactive internet training program and awareness of anosognosia
- **DEVELOP** an early childhood awareness and cause-related marketing plan to increase earlier interventions for serious brain illness [DONATE NOW]
- **LEAD** a coalition to Reclassify Schizophrenia as a neurological brain illness [SIGN OUR PETITION] and Urge the CDC to include Schizophrenia in the National Neurological Conditions Surveillance System (NNCSS) and the SAMHSA Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC) to work to reclassify [SIGN OUR PETITION]

**SARDAA is Launching Volunteer-led Chapters**

Founded more than a decade ago, SARDAA has thousands of supporters who help guide our work for people affected by serious brain illnesses. Our Chapter leaders will help determine our agenda, give us credibility across government, media and the public.

Chapters will provide community-based leadership by providing life-saving services and taking-action as well as educating their local communities about the risks of serious brain illnesses and help those impacted with support and education and knowledge that treatments are available.

Chapter Objectives:
Chapters work within their communities by advocating for comprehensive integrated care and treatment change in HIPAA, improvement and implementation of AOT for people affected by schizophrenia spectrum brain illnesses and by providing free services such as:

Chapter Implementation:
* Organize stakeholders, leverage community relationships and utilize social media to recruit Chapter Leaders and volunteer Ambassadors while also developing a base of supporters
* Leaders drive the Chapter's activities and dedicate around 5 hours per week to leading the Chapter
* Volunteer to make events successful and support the Chapter as their schedules allow
* Build infrastructure so standard chapter operating procedures can be executed
* Elect minimum of 3 Chapter Officers including a chapter president, Program and Community Outreach Chair and Fundraising Chair

Interested? [VOLUNTEER & FORM NEW CHAPTER HERE]

**SARDAA and The L.E.A.P. Foundation for research to Practice, Inc. Announce Formal Collaboration**

We are excited to work together, over a multi-year period, to assist families of persons with serious neuro-psychiatric brain illnesses and anosognosia, allied health professionals, criminal justice professionals, persons with serious brain disorders as well as others
involved in their care, recovery and safety.

Specific areas of collaboration will include the following focus areas:

- Providing educational support groups, referral services, and trainings for those affected by serious neuro-psychiatric brain illnesses;
- Assisting in the nationwide expansion and rollout of a virtual-based training protocol of the L.E.A.P. program;
- Co-developing a public awareness and cause-related marketing plan to increase public awareness of neuro-psychiatric brain illnesses and anosognosia;
- Assisting each Party in developing advocacy-related activities which have the potential to reduce discrimination in the illness, and re-invigorating our orientation towards timely and appropriate treatments as well as making incarceration and homelessness unacceptable outcomes.

Join us in urging the CDC to include Schizophrenia in the NNCSS as a step towards reclassification of Schizophrenia as a Neurological Brain Illness!

Ask the ISMICC to consider reclassification of schizophrenia spectrum illnesses as neurological brain illnesses!

Individuals with schizophrenia die on average 28.5 years sooner than other Americans. Sadly, 40% of this is due to suicide. Whether patients receive timely, appropriate treatment has great consequences. Not regularly taking antipsychotic medications is associated with a 12-fold increase in the risk of death and 37-fold increase in death by suicide. Unfortunately, up to 40% of individuals with schizophrenia are untreated (Treatment Advocacy Center). Many of the homeless population have a diagnosis of schizophrenia, with higher rates in younger persons (13% for 18–30 years old; 21% for 31–40 years old).

The Staggering Cost of The Current Situation Costs associated with schizophrenia of $375 Billion is disproportionately high relative to other chronic health conditions, reflecting both “direct” healthcare costs as well as “indirect” costs of lost productivity, criminal justice involvement, social service needs, and other factors beyond health care.

Reclassifying Schizophrenia as Neurological Would:
* Provide beds instead of incarceration/homelessness by circumventing the Institutions of Mental Diseases Exclusion (IMD Exclusion).
* Provide increased access to appropriate treatment by a comprehensive integrated team including psychiatrists, neurologists and other providers.
* Not change Medicare Part D/6 protected classes of drugs.

Outcome: Improved Diagnostic & Treatment Guidelines.

Our vision is that every person living with a schizophrenia-related brain disorder receives respect, appropriate treatment and an opportunity to live a meaningful and satisfying life in a compassionate community free of discrimination.

Sign the Petition to Urge the CDC to include Schizophrenia in the NNCSS
Sign the Petition to Urge the ISMICC to work to reclassify Schizophrenia as a Neurological Brain Illness!

SARDAA has Launched a Junior Board of Directors
The Junior Board is dedicated to helping achieve our goals,
including raising funds to support essential services for people living with serious brain illnesses. This is an exciting environment where young professionals can deepen their understanding of community issues, gain governance experience and socialize.

We are seeking interested people who meet the following:
- Personal connection to organization’s mission
- Active in their community with strong peer network; eager to fundraise in their social and professional circles
- Up-and-comer in their career; future leader; aged approximately 22-40

Contact Gordon.lavigne@sardaa.org if you are interested.

**New Corporate Advocacy Board Announced**

We have established a Corporate Advocacy Committee (CAB) to help link leading industry partners align common goals and accelerate corporate investment in SARDAA’s strategic initiatives.

- Comprised of distinguished industry leaders united in advancing the mission of SARDAA and educating millions about serious brain illnesses
- Helps set policy and our agenda and provides access across government, media, and allied industry stakeholders
- Shares their unique expertise and perspectives on the issues and needs facing those affected by serious brain illnesses

For more information, Contact Gordon.lavigne@sardaa.org if you are interested
Message from FFS, Family and Friends, Coordinator

The approaching holidays are upon us again, accompanied by its joys and stresses. A source, probably many, claim that a majority of Americans experience heightened stress during these times, and we as families and friends are no exception, likely at a greater level.

Those who know of Elizabeth Kubler-Ross and her great work in bringing the hospice movement to the U.S. may feel heartened at her advice to 'reframe the focus of our holiday activities from what we think the holiday should be to that of celebrating LOVE, experiencing it fully with meaning and intention'. Make conscious decisions appropriate for us and our loved ones...to 'park what should be and embrace what could be'. With Thanksgiving in mind that might mean instead of the expense and work of preparing a big meal, to plan on enjoying a meal out with those who 'value our company'....or to volunteer to help out at a community dinner for low income and homeless people. Thinking outside the box may return
the holiday to the time of gratitude it was intended.

With Heart,
Mary Ross

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**Message from SA Staff Supporter**

**Joining Conference Calls**

By Sandy Dimiterchik

I remember joining a SA conference call back in 2013. I had read about SARDAA on the Internet and was interested in how participating would work. I was nervous because I had never called in to a conference call before. So, I called in, and I was pleasantly surprised by what I found. Somebody asked, “Who called in?” since my call was accompanied by a bell tone. I gave my first name, and then the leader explained how the group worked.

Everybody took turns telling which step they were on, which was completely new to me. I had never participated in a 12-Step Program before, though in SA it is 6 Steps. Also, the leader talked about the term recovery, which was completely new to me. I had been struggling trying to figure out when I would reach my goal of being healthy, and according to the Blue Book that is used at each meeting, there was discussion about it being an ongoing progress that a person had to work at, unending. This was new to me. There was also talk of stigma and setbacks. I was amazed by what I heard – people with different schizophrenia spectrum disorders – united by the symptom of psychosis and the desire to live a high-quality life.

My life has been changed since then. My attitude is different, and I believe that recovery is possible for anybody with a severe brain disorder. I am so filled with hope for future treatments, as we change the world’s attitude toward us and our own attitude of how great our lives can be. I recommend getting a Blue Book, and reading not only the 6 Steps, but the personal stories of recovery. These stories are inspirational and life-changing.

Are you interested in meeting other people on the phone on a conference call who is a family member or friend of someone living with schizophrenia or a related disorder? Do you live on the West Coast? Here is a chance to receive training to guide family and friends of the diagnosed about the 6 Steps of Recovery. You will receive training materials and use the Blue Book format to lead meetings with a co-leader. For more information, contact the office at 240-423-9432 or info@sardaa.org. You can also directly contact me, Sandy Dimiterchik, at 832-439-1586 or sandy.dimiterchik@sardaa.org. I look forward to speaking to you and starting an additional FFS group!

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**Helpful Tools for the Holiday Season**

#1 Giving is less about money and “stuff” and more about appropriate time spent and caring given

#2 Enjoy the moment with the people you care about

#3 Be sensitive to your and other’s limitations

#4 Each day find at least ONE thing to be grateful for and if you can, write it down and keep a calendar or list

#5 YOU ARE NOT ALONE! – Talk with your friends and family who understand and can empathize with you.
Be realistic in self expectations:
What can you afford?
What is too much stimulation?
What is too much food?
What is too much drink?
How much time can you really devote?
How much time do you need for yourself?
What is a NEED and what is a Desire?

Be realistic in expectations of others:
People have many people, tasks and things on their mind
People have a desire in their heart but might not have as much
time to give as
you would like them to give you
People have limited time
People have limited funds

Get the appropriate amount of rest

Eat foods that are light on carbohydrates and sugar
We don’t need to eat everything that looks and tastes amazing -
a small bite
can satisfy the desire

Choose healthy stress-relieving tools
Avoid alcohol
Do not use illicit drugs or medications not prescribed for you
What is helpful for you?
Music, reading, relaxation exercises, sports, what is helpful
for YOU?

Reach out to your support system as soon as you feel the need. YOU ARE NOT ALONE!

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Congratulations to Grace Lee who received
The Walk’s Lime Green Baccarat Butterfly Award
for raising $2725.00 as of Oct. 6, 2018

Walking for SARDAA at the Walk for Mental Health Awareness Houston
Patrick McIlvain, The Walk Houston, Director
Personal Story of SA Members
Phil C.
Because I was schizophrenic and could broadcast my thought. Thought broadcasting is believed to be a sure sign of schizophrenia, but few believed it was real. What happened next is a sure sign that in my case, it WAS real!

READ PHIL's Story HERE

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

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

The Bloc - HVoS was awarded at The Creative Floor Awards in London!
http://thecreativefloor.com/awards/2018-winners/
Thank you to theBloc, especially Brit Till, Sharon Howard-Butler, Ian Fowler, Craig Kabhrel for partnering in this extraordinary project and donating their time, technical expertise and phenomenal artistry!

Very special thanks to all of the BRAVE individuals who shared their stories: John C., Daniel L., Rob L., Shari S., Garen S., Brandon S., Morgan S., Susan S., Lance S., Emmett B., Leslie B., Katie L., Dave L., Doris O., Mike A., Jess and Ismael C.

It has been a powerfully emotional, beautiful and intimate journey of strength and hope.
https://hearingvoicesofsupport.org/

Dr. Tim Murphy, SARDA board member, presents at the annual APNA conference. His message about the need for unity in advocacy for the most seriously ill was enthusiastically received.
Computer-Delivered Cognitive Training Significantly Helped Schizophrenia Patients in Rehab Setting
Brain & Behavior Research Foundation
Cognitive difficulties experienced by people with schizophrenia are the symptoms of the illness that tend to have the greatest impact on daily functioning and overall quality of life. Individuals who have reduced interest in activities, problems remembering and learning, or interpreting verbal cues, find it very difficult to hold jobs or cultivate social relationships that are central in normal functioning.

READ MORE

Functional Imaging Supports Neurodevelopmental Hypothesis for Schizophrenia
Psychiatry Research
Marilynn Larkin
October 15, 2018
Schizophrenia is a neurodevelopmental, rather than a neurodegenerative disorder, meaning cognitive control deficits are present at onset and not the result of brain deterioration, a new study suggests. Previous studies have yielded mixed results with respect to the etiology of schizophrenia. Some support the concept that the disorder occurs when prenatal insults or genetic deviations interact with the environment, leading to psychosis onset in late adolescence/early adulthood (neurodevelopmental model); other studies show brain structural anomalies such as reduced gray matter, supporting the concept of neurodegeneration.

READ MORE

Prescribing Antipsychotics in Geriatric Patients: Focus on Schizophrenia and Bipolar Disorder
In this context, psychiatrists need information on the relative risks of antipsychotics for older patients. This 3-part series summarizes findings and recommendations on safety and tolerability when prescribing antipsychotics in older individuals with chronic psychotic disorders, such as schizophrenia, bipolar disorder, depression, and dementia. This review aims to:
• briefly summarize the major studies and analyses relevant to older patients with these diagnoses
• provide a summative opinion on safety and tolerability issues in these older adults
• highlight the gaps in the evidence base and areas that need additional research.

READ MORE

Rasmussen Reports, Seriously Mentally Ill
A Commentary By John Stossel
October 3, 2018
They live on the street, often foraging through dumpsters. Some threaten us. Occasionally, they assault people.

Thousands of mentally ill people cycle in and out of hospital emergency rooms. They strain our medical system, scare the public and sometimes harm themselves.
Most, says DJ Jaffe, are schizophrenic or bipolar and have stopped taking their medication.
Jaffe gave up a successful advertising career to try to improve the way America deals with such people.

"John Hinckley shot President Reagan because he knew, not thought, knew that was the best way to get a date with Jodie Foster," Jaffe tells me in my latest internet video collaboration with City Journal.

**Patient and Family Schizophrenia Education Day, Progress in Schizophrenia**
November 10, 2018
The Starr Center Auditorium, Boston, MA
The Massachusetts General Hospital Department of Psychiatry invites you to attend a patient and family schizophrenia education day, Progress in Schizophrenia.

This exciting event will offer an update on new research findings and important clinical topics for patients with schizophrenia and their families. In the morning, participants will learn about updates on early brain development and risk for schizophrenia and a cannabis update. The afternoon will feature a talk on the use of information technology in Schizophrenia, and we will also feature a panel of families who will share their experience with, helping loved ones recovering from psychosis. Our last talk will be on, new drug development.

**We must treat mental and bodily health the same. It’s a matter of human rights**
Rosalynn Carter, Patrick J. Kennedy
September 28, 2018
Rosalynn Carter, former first lady of the United States, is an advocate for mental-health care through the Carter Center. Patrick J. Kennedy, former U.S. representative (D-R.I.) from 1995 to 2011, is the founder of the Kennedy Forum and author of “A Common Struggle: A Personal Journey Through the Past and Future of Mental Illness and Addiction.” Almost 10 years have passed since Congress required that insurers offering mental-health services for illnesses of the brain, such as depression or addiction, do so no more restrictively than illnesses of the body, such as diabetes or cancer. And yet most insurers today still do not comply with the law.

Mental-health parity is more important now than ever before, considering the rising numbers of overdoses and suicides nationwide. But state and federal investigations have shown that mental-health and addiction treatment are frequently far more onerous to manage.

**A Revealing Genetic Comparison of Schizophrenia and Bipolar Disorder**
Brain & Behavior Research Foundation
Researchers have taken an important step toward understanding the relationship between two of the most serious psychiatric disorders, schizophrenia and bipolar disorder. For years, they have known that the two share certain symptoms, and presumably, underlying genetic disturbances. Studies of families have shown that someone with an immediate family member with schizophrenia not only has about 10 times the normal risk of schizophrenia, but also an increased risk of bipolar disorder.

Understanding how the symptoms of the two relate to each other is
an important part of the effort to improve diagnosis and personalize treatments for better patient outcomes.

**Crisis Intervention Team (CIT) Methods for Using Data to Inform Practice: A Step-by-Step Guide**
SAMHSA
This guide helps local systems use data to implement Crisis Intervention Team programs that can improve the safety and effectiveness of law enforcement response to people experiencing behavioral health crises. It provides information about building necessary partnerships, documenting program activities, identifying key metrics, establishing data collection processes, analyzing and reporting data, using data to improve programs, and expanding capacity to collect and use data.

**2016 Mental Health Client-Level Data Annual Report**
SAMHSA
This report presents results from the Mental Health Client Level Data and Mental Health Treatment Episode Data Set for individuals receiving mental health treatment services in 2016, as well as selected trends in data collected from such individuals between 2013 and 2016. It provides information on mental health diagnoses, mental health treatment services, and demographic and substance use characteristics of individuals in mental health treatment in facilities that reported to individual state administrative data systems.

**Providing Integrated Access to Health Services in Nashua, New Hampshire**
Healthy People 2020
September 27, 2018
Access to health care is a key determinant of physical and behavioral health outcomes. Regular access to primary health services is critical for preventing and detecting diseases, ensuring comprehensive treatment, and improving overall quality of life. This Healthy People 2020 Update profiles the Partnership for Successful Living in Nashua, New Hampshire which takes an integrated approach to health care. The Partnership’s goal is to provide comprehensive care that’s easy for vulnerable populations to access, with services ranging from primary care, behavioral health, and oral health to housing support and treatment for substance use disorder.

**Fact Sheet: Overview of Law Enforcement-Mental Health Resources**
Bureau of Justice Assistance
This fact sheet provides an overview of Bureau of Justice Assistance resources and initiatives about the intersection of criminal justice and mental health.

**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](#).

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**AutoCruitment**

Optimizing the Science of Patient Recruitment

Are you (or someone you care for) Diagnosed with Schizophrenia?
The Enhance or Advance clinical study is evaluating an investigational treatment for schizophrenia to determine if it is effective when used in addition to an already prescribed antipsychotic medication. Participants (Aged 18 – 55) will receive all study-related care from a doctor at no cost.

Volunteers who take part in the study will also be compensated for their time and travel expenses. [Apply here](#).

SARDAA is providing information and convenience for the public, and does not constitute endorsement, recommendation, or favoring and makes no claims, promises, or guarantees about this clinical study and expressly disclaims liability.

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**Schizophrenia Health Storylines™ Mobile App**

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. [Download the app today!](#)

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**Donate to SARDAA**

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.

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, 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](http://smile.amazon.com/ch/33-1213657), start shopping and support us every time you shop.**

Shop with [PayPal](https://www.paypal.com) 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 **XA142**

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**Help Change Lives -- Donate Now**

Thank you to those who already made a donation. Every contribution makes a difference.
Sincerely,
Jordan Helwig, Creative Designer
Angel White, Editor