



Siblings & Offspring

April 2019

CONNECTIONS



Maryland

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ONE FAMILY’S JOURNEY TOWARD HOPE

This article is reprinted from “Siblings and Offspring” published in 2003. NAMI Maryland values research and our partnership with NIMH. Please see the end of the article for more information.

It has been almost a year since our family found a description of a schizophrenia sibling study in the *NAMI Advocate*. This research is an ongoing study of the National Institute of Mental Health (NIMH), in Bethesda, Maryland, comparing the genetic and neurobiological differences among hundreds of people with schizophrenia or schizo-affective disorder and their siblings.

Of eight siblings, I am the only one with a schizo-affective disorder. Our family applied to the sibling study knowing that this research is generating information to give neuroscience the keys that are beginning to break into the complex biological codes of this illness. My brother Michael’s business is providing computer technologies to researchers studying the genetic abnormalities within the full and immensely complex

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WHAT CARING ADULTS CAN DO FOR THE CHILD WHOSE PARENT HAS A MENTAL ILLNESS

- Tell the child what illness their parent has, its symptoms and prognosis. Discuss the medications their parent will be taking. Give them as much information, at an age-appropriate level, as they seem to want to have. It is very frightening to be kept in the dark.
- Give the child frequent opportunities to discuss their fears, questions and concerns.
- Listen to the child without judgment. Assure the child that all of their feelings are valid and okay.
- Make reading material available. For a young child, reading together creates a positive atmosphere for further discussion and questions. But for the older child, leave the material in an accessible place and allow the child to read when they are ready. Don’t push or question. The child may be uncomfortable talking about the subject (or feel disloyal to the parent).
- Whenever possible, allow the child to participate in decisions that affect the whole family.
- Create opportunities for the family to be “normal”. For example: Going to church together, taking a vacation or holiday, going school shopping. It is

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ONE FAMILY'S JOURNEY TOWARD HOPE

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human genome. Michael recognized the neuro-imaging and genetic technologies of NIMH as the most advanced tools of neuroscience in the world.

This study was an opportunity for eight siblings to add an unusual wealth of information to schizophrenia research. We embraced the opportunity to benefit others with this disorder. We were accepted into the study and were welcomed by NIMH as respected and valued partners in this pioneering research. They arranged our flight schedules, hotel bookings, and testing days to maximize the rare time we had to spend together. The study was a fast moving two days of detailed magnetic resonance imaging (MRI) scans, interviews, and neuropsychological testing. Other than a routine blood draw, there was no invasive testing.

For our family, the long road to the sibling study began 28 years ago in 1975. I was hospitalized after a three-year slide into a psychotic illness. I fell into the hands of a psychiatrist who psychoanalyzed my hallucinations and assessed my entire family as "schizophrenogenic".

Despite the neurobiological anarchy sweeping through my life like a forest fire, reality began to dawn on me by 1979: I had seven brothers and sisters, and none of them were like me. They were all working, going to school, or in college. We were of the same parents, and we were all raised by a courageous and hardworking single mother who loved us all. I was different from early in life. As a young adult, hallucinations and depression were taking over my entire life.

None of my siblings had ever been brought to their knees as I had by visions and voices and depression that paralyzed even my will to live. I knew my family was not doing this to me; there was something wrong with my brain. I found another psychiatrist, who remains with me to this day as a constant source of expertise and encouragement.

Looking back from 2003, I call the primitive and hopeless psychiatry of the 1970s the "dungeons of the day". Old Freudian ideas that had twisted the psychiatry of schizophrenia away from the brain onto blaming

families were still widely held. It was a dated era still spun with mythically monstrous mothers named and blamed as "schizophrenogenic".

The psychoanalytic psychiatry of the 1970s perpetuated the influence of a century of Freudian ghosts that linger to this day as the deep shroud of shame, guilt, and misunderstanding that continues to obscure the neurobiological legitimacy of this illness.

Before we left NIMH, I talked to Dr. Michael F. Egan, the lead investigator of the sibling study. I told him what it was like for me coming from the "dungeons of the day" to be, 28 years later, working with the NIMH as a full

and respected partner in research that I thought I would never see happen in my lifetime.

Dr. Egan told me that they have good evidence directly from the sibling study that five or six genes increase the risk for schizophrenia. The empowering character of this progress is a clear and bright light of new hope and promise moving at light speed in the right direction. It is a privilege to be a part of this revolution in



neuroscience.

At NIMH, I saw my brothers and sisters in the full light of their loyalty and love. They were all indicted as "schizophrenogenic" 28 years ago, but when this illness threatened to take me away from them, they rose to the challenge and held out their hands to me in the moments I otherwise would have drowned. Six of them were younger than I was when this illness swept out of hell, yet they have traveled this distance with me unafraid. They have made my life richer, funnier, and filled to overflowing as a sister, an aunt, and a friend.

Without them, it would have been a dark and difficult journey. With them, we have walked this 30-year road out of darkness into daybreak.

by Peggy Symons, from www.nami.org

Learn about current NIMH research studies at:
<http://ow.ly/CqTa300oQVf>

WHAT CARING ADULTS CAN DO FOR THE CHILD WHOSE PARENT HAS A MENTAL ILLNESS

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- difficult to feel “normal” when your parent has a mental illness.
- Recognize the child’s accomplishments in school, sports, music, etc. Encourage the child to participate in activities that are important to them personally and to develop their own talents.
 - Let the child know that it’s okay to have fun, that their parent would want them to have a normal, happy life in spite of the family situation.
 - Assign the child an appropriate level of responsibility in the care of the home, other siblings and the parent with a mental illness. Children can be so anxious to help that they will take on an overwhelming burden of responsibility. It is up to adults in their life to know how much is too much.
 - See that the child understands that no matter what caretaking role they have, the child is in no way responsible for the onset of the illness, its symptoms, severity or ultimate outcome. No child can control mental illness, but many believe that they can if only they work hard enough at it.
 - Share the work to be done among all siblings, according to their ability to participate. Too often one child becomes the caretaker. All children need to feel involved.
 - If the parent is hospitalized, give the child the option to visit or not. Psychiatric wards and state hospitals can be very frightening to a child. They are exposed to other patients besides their own parent, not to mention barred windows, locks and fences.
 - If your child chooses to visit, prepare them in advance as to what to expect. Explain what they will see and why. Talk about it afterwards.
 - Talk about what happens in the hospital, the treatment their parent will receive, how long they will be hospitalized, what to expect when the parent returns home. Be realistic.
 - A talk with the parent’s doctor may be reassuring for the older child. Also, it may give the child an opportunity to ask questions that they would hesitate to ask a parent.
 - Take steps to ensure the safety of the child at all times. While most people with mental illness are not violent, the unpredictability of the illness may make the child feel threatened. A child experiences so much guilt about even having this fear of their own parent that he is not likely to mention it. Make arrangements for the child before and after school and give serious thought before utilizing a child as a sitter for the parent with a mental illness.
 - Learn coping skills as a family. There are more effective ways to communicate with a person with psychosis. Help the child with this.
 - As a parent recovers from a psychotic break, there is a readjustment and reintegration into the family. The older child may have difficulty accepting the return of “mom” or “dad”. Talk this out as a family. Recognize how this will impact the children in the family.
 - Make sure that the family is represented at the child’s important occasions such as graduations, religious ceremonies and recitals.
 - Encourage children to join a professionally-led, age-appropriate support group, available in some communities.
 - Offer physical affection regularly. A hug or a smile may be really needed.
 - Foster a sense of humor. Mental illness is serious and tragic, but a sense of humor can be a valuable tool for coping with the bizarre behaviors that accompany delusions and hallucinations.

*Reprinted from handouts provided in
NAMI’s Family-to-Family Education Course*

Editor’s Note:

Children can be very resilient. Family members and others can be additional source of resiliency. It is important to identify and support resilience and encourage development of additional resiliency factors.

One of the common factors associated with successful adaptation and coping is identified as resilience of individual family members. Resilience can be generally defined as the ability to “bounce back” to healthy functioning when faced with significant stressors and events. The National Network for Family Resiliency defines resilience as “the family’s ability to cultivate strengths to positively meet the challenges of life.

COPING TIPS FOR ADULT CHILDREN AND SIBLINGS

If you find it difficult to come to terms with your sibling's or parent's mental illness, there are many others who share your difficulty. Most siblings and adult children of people with psychiatric disorders find that mental illness in a brother, sister, or parent is a tragic event that changes everyone's life in many basic ways. Strange, unpredictable behaviors in a loved one can be devastating, and your anxiety can be high as you struggle with each episode of illness and worry about the future. It seems impossible at first, but most siblings and adult children find that over time they do gain the knowledge and skills to cope with mental illness effectively. They do have strengths they never knew they had, and they can deal with situations they never even anticipated.

A good start in learning to cope is to find out as much as possible about mental illness, by both reading and talking with other families. NAMI has books, pamphlets, fact sheets, and videos available about different illnesses, treatments, and issues you may have to deal with, and you can join one of the thousands NAMI affiliate groups throughout the nation. (For other resources and to locate your state or local NAMI affiliates, call the NAMI Helpline at **(800) 950-6264**.)

Here are some things to remember that should help you as you learn to live with mental illness in your family:

- You cannot cure a mental health disorder. No one is to blame for the illness.
 - Mental health disorders affect more than the person who has it. They affect the entire family.
 - Despite your best efforts, your loved one's symptoms may get worse. But they may also improve.
 - If you feel extreme resentment, you are giving too much.
 - It is as hard for the parent or sibling to accept the disorder as it is for *other* family members.
 - True acceptance of the disorder by all concerned may be helpful, but it is not necessary.
 - A delusion has little or nothing to do with reality.
- Delusions do not respond to reason.
- Separate the person from the disorder.
 - It is not OK for you to be neglected. You have emotional needs and wants, too.
 - The illness of a family member is nothing to be ashamed of. The reality is that you will likely encounter stigma from an apprehensive public and other family members.
 - You may have to revise your expectations of the person with the mental illness, as well as of yourself and others.
 - You may have to renegotiate your emotional relationship with the person with a mental illness.
 - Acknowledge the remarkable courage your relative may have shown when dealing with a mental health disorder.
 - Generally, those closest in sibling/offspring order and gender become emotionally entangled while those further away in age or of another gender may become estranged.
 - Grief issues for siblings are about what you had and lost. For adult children, they are about what you never had.
 - After denial, sadness, and anger comes acceptance. The addition of understanding yields compassion.
 - It is absurd to believe you can correct a biological illness such as diabetes, schizophrenia, or bipolar disorder with talk, although addressing social complications may be helpful.
 - Symptoms may change over time while the underlying disorder remains.
 - You should request the diagnosis and its explanation from professionals.
 - Mental health professionals have varied degrees of competence.
 - You have a right to ensure your personal safety.
 - Strange behavior can be a symptom of the disorder. Try not to take it personally.
 - Don't be afraid to ask your sibling or parent if they are thinking about hurting himself. Suicide is real.
 - Don't shoulder the whole responsibility for your

relative with a mental illness yourself.

- The needs of the person with the mental illness do not necessarily always come first.
- If you can't care for yourself, you can't care for another.
- You are not a paid professional caseworker. Your role is to be a sibling or child, not a parent or caseworker.
- It is important to have boundaries and to set clear limits.
- If a relative with a mental illness has limited capabilities, it doesn't mean that you expect nothing of them.
- Many times capabilities change with the severity and ups and downs of the illness. Look for current strengths and never give up hope for improvement.
- It is natural to experience many and confusing emotions such as grief, guilt, fear, anger, sadness, hurt, confusion, and more. You, not the individual with a mental illness, are responsible for your own feelings.
- Inability to talk about your feelings may leave you stuck or "frozen."
- You are not alone. Sharing your thoughts and feelings and getting practical suggestions from a peer support group is helpful, enlightening and empowering.
- With education and support, you may see the silver lining in the storm clouds as you gain: increased awareness, maturity, sensitivity, receptivity and compassion. You may become less judgmental and self-centered: a better person.
- Mental illness is not on a continuum with mental health.
- Seek out the best experts available in your community.
- Ask for a joint conference with the treatment team and the adult patient, showing concern for confidentiality.
- Always be prepared for a crisis but never, never give up hope!

Reprinted from www.nami.org, with some additions from the NAMI Family-to-Family Education Program and NAMI members.

Objective Life Burdens of Adult Siblings and Children of People with Mental Illness

In the **NAMI Family-to-Family Education Program**, different “relative groups” discuss the objective burdens each group bears. Adult siblings and adult offspring consistently report the following issues:

1. Disproportionate attention being given to the sibling with the illness or parent; an atmosphere of secrecy, confusion, silence, shame; witnessing terrifying psychotic breaks and personality changes in a family member with a mental illness.
2. Being menaced or hurt by someone who is supposed to be a caring, protective family member; experiencing the sibling or parent as “**bad**” rather than “**with an illness**”.
3. Bearing the social stigma of having a “**strange**” family member.
4. Handling the emotional needs of the caretaking parents or the neglected parent spouse.
5. Having more chores and responsibility; having to “**grow up fast**”; needing to be a “**super**” child to “**make up**” for the parent or sibling with a mental illness.
6. Worry that **you** caused the illness, or that **you** will get the illness, or **you** will make the parent or sibling worse.
7. Worry about how much you should do for the family member with a mental illness; worrying about the time when the caretaking parent or parents die and it will all be your responsibility.

MEETING THE NEEDS OF YOUNG FAMILY MEMBERS OF SOMEONE WITH A MENTAL ILLNESS

Mental illness is a catastrophic event for the family system that affects all family relationships and all members of the family. A wide range of resources and services may be helpful under these circumstances, including improved services for the family member with mental illness, respite care for family caregivers, support for adult members of the family, and special assistance for young family members.

Coping with early onset of a brain disorder in a child or adolescent is a daunting experience for parents, but too often other family members, especially the children, tend to get overlooked, or are protected from knowing the truth of their sibling's illness or even a concrete diagnosis. Frequently, these siblings grow up blaming themselves, feeling neglected and unloved by their parents, or fear that this terrible illness can somehow be contagious or inherited by their own offspring. It is important to strengthen and support the family system as a unit, providing the services necessary for meeting the needs of all family members. Here are some suggestions on ways to support all the young family members needs during these trying times.

FIND BOOKS AND ARTICLES ABOUT THE EXPERIENCES AND NEEDS OF SIBLINGS AND OFFSPRING OF PEOPLE WITH MENTAL ILLNESS.

Many resources are available, including books for young children who have a close relative with mental illness. There are also books and articles for adult family members, such as the spouse or parents of the relative with a mental illness, that may assist them in meeting the needs of young children in the family. Call the NAMI Helpline at (800) 950-NAMI. Request a list of suggested books and publications.

REACH OUT TO YOUNG SIBLINGS AND OFFSPRING AS EARLY AS POSSIBLE.

All young family members are profoundly affected by the mental illness of a beloved parent or sibling. There is no way to shield children from this family event, but

the negative consequences may be diminished if there is open communication within the family and continuous attention to their needs. Encourage young family members to ask questions and to share their feelings with you. Reassure them that they are not responsible for the illness.

MEET NEEDS FOR INFORMATION, SKILLS, AND SUPPORT IN AGE-APPROPRIATE MANNER.

As with other family members, young family members need information about mental illness and its treatment, strategies and skills for coping with the mental illness and its consequences for their family, and support for themselves. These needs may be met by adult members of the family, by caring people outside the family, or by professionals.

FORM A NETWORK OF PARENTS AND PROFESSIONALS COMMITTED TO MEETING THE NEEDS OF YOUNG FAMILY MEMBERS.

Many other family members share your concern for children and adolescents who are growing up with mental illness in their families and can offer valuable suggestions for meeting their needs. Similarly, professionals who work with children and adolescents can offer consultation and services.

- Maintain a life span perspective that acknowledges their changing needs at different stages of development; seek out services or develop services if none are available. A full range of services for families consists of non-clinical services, including educational programs and support groups, and clinical services, including various forms of psychotherapy. All of these services offer potential benefits for family members at all stages of development.
- Work to develop a specialized staffed support group that provides information about mental illness, practical advice, and contact with other



young siblings or offspring of consumers of mental health services. Young family members can benefit from a group or other activities designed specifically for them. Groups can be offered for elementary, junior high, or high school students, and can be located in a variety of settings, including a local NAMI affiliate, a school, or mental health clinic.

- Consider personal counseling for young family members who are experiencing special difficulty. Some young family members may experience intense and unresolved problems in response to the mental illness in their families. Although they are likely to benefit from a specialized group or program, these family members may also profit from personal counseling with a child or adolescent therapist. Your child's teacher, guidance counselor, or pediatrician can help you decide whether personal counseling is appropriate for a particular child or teenager.
- Encourage programs in schools that can educate the school population about serious mental illness. Given the incidence of serious mental illness, there are legions of children and adolescents who are living with mental illness in their families. Enlist the assistance of teachers, principals, guidance counselors, and school psychologists, who can serve as a support system for young family members. This

will be an important tool for educational professionals to help siblings as well as other family members of individuals with a mental illness.

- Help young family members understand and adapt to the mental illness in their family. Adaptation to mental illness requires many coping strategies and skills. For example, young family members need to understand the impact of mental illness on their own lives, to establish realistic expectations for themselves and other family members, and to develop an appropriate relationship with the relative who has mental illness.
- Assist them in maintaining the integrity of their own lives and in developing constructive long-range plans. Mental illness in the family often functions as an energy sinkhole consuming valuable energy needed by young family members for their own development. It is essential to support them in functioning effectively in their school work, in their peer relationships, and in activities outside the family. They often need reassurance that their needs matter and that they will be supported in achieving their goals.

by Diane T. Marsh, Ph.D.

HOW PROVIDERS CAN HELP ADULT CHILDREN AND SIBLINGS

The following information represents a composite of responses from family members who have participated in NAMI training programs, given around the country, to introduce professional providers to the “Relative Groups” in families of individuals with serious mental illness.

HELPING SIBLINGS

Many siblings want providers to listen to them, to ask what they know, think and feel about their sister or brother with a mental illness, and to let them be involved constructively by helping in some way.

Siblings also need providers to understand and support them when they feel they must step out of the family problem, to empathize when they are torn between the things they need to do to move their own life along and the obligation they feel to help their parents and their sibling with a mental illness.

Sibling’s survival guilt can arouse many fears about their own mental well-being and influence many of their decisions about life choices. These issues are very real for young adult siblings who are just starting out into the world; they need to talk about these feelings and to explore whether their sibling’s illness might be casting a shadow on any part of their lives.

Oddly enough, many siblings report that providers (and even people in their own families) do not register the enormity of sibling loss or comprehend the depth of sibling grief. Perhaps this is part of family denial, of parents not wanting to see any more “hurt” children in their family. Perhaps it is the way people neglect survivors’ feelings because, after all, they have been lucky enough to survive. Sibling loss is normally intense and is reactivated at every developmental milestone throughout life. Providers can help siblings with the grieving process at any one of these points.

Siblings tell us that they have commonly blocked the trauma of scenes and events that they witnessed when

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their sibling was having a psychotic episode. This includes traumatic things that happened to them, like being threatened or abused. Providers need to understand that siblings who have endured these ordeals often want to detach from the sibling with a mental illness. The sibling can come to understand that these behaviors are illness-related, but it takes time and courage to overcome this kind of trauma.

Many siblings report that they feel invisible in their family after mental illness strikes—that their needs get lost in the intense demands made on the family by their sibling with a mental illness. Siblings in these families must bear witness to the extraordinary stresses imposed on their parents and often do not want to burden their parents further with demands of their own. Sibling support groups provide a safe and welcome place for siblings to talk about these issues.

HELPING ADULT CHILDREN

The vast majority of people who are the children of individuals with mental illness do not develop mental illness themselves. It is important for providers to de-stereotype this population, which has often been portrayed as inescapably “disordered”. Each adult child will have his unique story to tell and should not be negatively “categorized” due to the circumstances of mental illness in a parent.

However, most adult children will tell you that no one can come through this experience unscathed. Depression, anxiety, feelings of hopelessness and defeat, repressed anger, and passivity all combine to form a persistent dysthymia that can rob life of happiness. Many adult children appear to be exceptionally self-reliant and competent, masking the conflict they have about dependency needs and their reluctance to ask for help; rarely do they allow others to glimpse the sadness and uncertainty they feel inside. Adult children can be greatly assisted by psychotherapy; special support groups are now available, as are educational and self-help books relevant to their family experience.

Studies indicate that having a parent without a mental illness in the mix, or a sustaining sibling relationship, will mediate the stress involved in coping with a parent with a mental illness. Without these supports, life for the child is often terrifying and traumatic, and worse if the



family must endure the more severe spectrum of illness. Children caught in this situation need networks of support outside the family, and must be helped to create a psychological buffer between themselves and the behavior of their parent with a mental illness.

Adult children mourn the loss of their childhood, the loss of a carefree, stable family structure, and the loss of their own young potentials. Many children coming through this hardship are “late-bloomers”; so much of their development and self-confidence is placed on hold while they cope with the parent. Others speak movingly about how odd it feels to outgrow a parent, to develop beyond the capacities of a person you always expected to be “ahead” of you, showing the way. Many report a sense of dread at the prospect of “signing-on” again to care for the parent with a mental illness as the parent becomes older. These conflicts and ambivalences need to be treated with empathy and respect.

Many adults children relate that they were told nothing about what was wrong with their parent with a mental illness—that even after growing to adulthood, they are still “in the dark” about the parent’s diagnosis. It is paramount for mental health professionals to provide education and guidance to children, to help them identify illness behaviors and to consult with them about family decisions made to accommodate the parent with a mental illness.

The most important role for providers in helping children of a parent with mental illness is a preventive one—that is, giving the parent sufficient services and supports to keep the illness (and the family) stable. Whenever children are involved in a family with a parent with a serious psychiatric illness, the family should be offered supportive family consultation and family education.

MARYLAND PSYCHIATRIC RESEARCH CENTER STUDY

Researchers at the Maryland Psychiatric Research Center in Catonsville, MD can Test for a Blood Draw at a Quick Visit

There is growing evidence that schizophrenia may be linked to inflammation resulting from an immune reaction to gluten, a protein found in wheat, barley and rye. This is found in about 1/3 of people with schizophrenia.

We have a study opportunity to get tested for these antibodies called antigliadin antibodies (AGA IgG) and you will find out if you are positive. If you are positive, you will have the opportunity to possibly participate in a separate follow-up clinical trial.

Opportunity to Get Tested for Gluten Sensitivity Which May be Linked to Schizophrenia Symptoms



If You Test Positive You Have the Opportunity to Participate in Another Study

The purpose of the clinical trial is to conduct a confirmatory double-blind randomized controlled trial in an inpatient setting to test the effects of a tightly controlled gluten-free diet (GFD) in people with schizophrenia or schizoaffective disorder who have antibodies to gliadin (AGA IgG). As part of the project we will also measure cognitive symptoms, changes in peripheral and central inflammation as well as gut/blood brain barrier permeability. You will have the opportunity for optional neuroimaging to test brain activity.

After the completion of the 5 week confirmatory study, we will discharge participants and follow them for 8 weeks in their own environment to test the maintenance of the effect following the stringent GFD, and provide education on gluten free shopping, cooking and eating. Study visits weekly will generally consist of a blood draw, vital signs, and side effects check as well as gluten free cooking and education groups. Participants are compensated for their time.

The study is being conducted by Dr. Deanna Kelly <http://www.medschool.umaryland.edu/profiles/Kelly-Deanna/> and her team at the Maryland Psychiatric Research Center, Treatment Research Program in Catonsville, MD, part of the University of Maryland School of Medicine and in collaboration with Dr. William Eaton and his team at John's Hopkins University in the Bloomberg School of Public Health.

For more information contact Megan Powell: 410-402-6413 or MMpowell@som.umaryland.edu

NIMH RESOURCES



Los niños y la salud mental
¿Es solo una etapa?

A Spanish version of NIMH's **Children and Mental Health** brochure is now available! This brochure on children's mental health includes information on when to seek help, steps for parents, evaluation, treatment, choosing a mental health professional, working with a school, resources, and clinical trials.

<http://ow.ly/URUp300jjLZ>

A Spanish version of NIMH's **Borderline Personality Disorder (BPD)** brochure is also now available. This brochure discusses BPD, including signs and symptoms, causes, diagnosis, treatment, co-occurring illnesses, associate suicide and self-harming behaviors, and clinical research.

<http://ow.ly/499Y300jjST>

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Documents and information submitted to the State of Maryland are available from the Secretary of State for the cost of copying and postage.