Self-Determination — What’s It All About?

“Self-determination” is a term gaining wider use and acceptance in the mental health community. But what does it mean?

Self-determination means that people are active participants in their families and communities. “When people talk about self-determination, they aren’t talking only about self-management of an illness, as important as that is,” says Judith Cook, Ph.D., Director of the Center on Mental Health Services Research and Policy of the University of Illinois-Chicago (UIC). “It also means having the right to freely choose how to live, vote, work, raise families, and socialize.”

Advocacy for self-determination grew out of the disability rights movement in the early 1990s. Advocates define self-determination as five things:

**Freedom:** Deciding for yourself how to work, live, and love, and what kinds of support you need in your life.

**Authority:** Having control over your own money, having the right to vote, being able to sign legal documents for yourself, and being able to decide how service dollars are spent on your own care, rather than a provider agency making this decision.

**Support:** Having resources and assistance of your own choosing to help maintain your wellness and set and meet new life goals.

**Responsibility:** Many people have had self-responsibility taken away from them when symptoms of their mental illness become severe. They, and others in their lives, often are afraid of failure or disappointment. But self-determination means that people, regardless of their illness, need to take some risks and try new things to learn about themselves and what helps them, at their own pace.

**Participation:** People with illnesses or disabilities must be included in the re-design of the human service system. New support programs must be created using recovery methods people have tried and found beneficial. A system that helps people can’t work without the input of the people it is supposed to help.

In the U.S. today, many individuals with serious mental illness do not have as much self-determination as they would like. To change that, many have organized to demand their basic freedoms and rights. “More and more, human service systems are accepting the importance of personal self-direction in treatment.” says Jessica Jonikas, Managing Director of the UIC Center. “A focus on self-determination can help people with mental illnesses create more meaningful lives.”

To find out more about self-determination and how you can be a part of the positive change, visit www.peersupport.org.

Adapted from:


President’s Outlook

Lydia Lewis

It seems like just yesterday I joined this organization, yet this June I completed eight years at DBSA. I have never held a position so fulfilling—a position where I have met so many amazing people and worked with a staff so dedicated to a mission—many because of their own struggles with depression or bipolar disorder.

We have a far more exciting anniversary to celebrate. This year marks 20 years since the incorporation of DBSA. This anniversary celebrates all of us—everyone who lives with, struggles to overcome, or cares for someone with depression or bipolar disorder.

Like so many others, I suffered for years with my illness feeling alone, resigned to never getting better, and facing consequences caused by my symptoms. I didn’t know I could demand better treatment or that I could be free of suicidal thoughts. DBSA’s founding came more than two decades after the onset of my illness. Who knows how my life may have been different if I’d found DBSA sooner?

DBSA touches the lives of more than four million people who contact us every year. We are there when people need us most, providing Hope, Help and Support. In this anniversary year we will encourage our fellow travelers in many ways.

Hope: In honor of 20 years of peers helping peers, DBSA will be holding Ceremonies of Hope across the country, where everyone can light a candle to recognize a loved one, supporter or someone who is still struggling, to show we believe in a better tomorrow.

Help: Because DBSA is patient-run and directed, we know what’s needed to achieve and maintain wellness. We know that it takes far more than treatment; it takes active participation in our recovery. Over the course of the year, we'll be offering 20 new resources that can help all of us on our recovery journey. For more information on the first five resources, visit our web site or call our toll-free number.

Support: DBSA is a leader in a new approach to recovery. In our Peer Support Specialists Program, those who are farther along on their wellness journey can be trained and certified in helping others. In addition, we are developing some new, exciting programs that will allow our DBSA chapters to reach out to their communities in new ways.

There are millions of people looking for help, hope and support. DBSA stands ready. With your help we'll move forward into our next 20 years with as much enthusiasm as we had when we began our journey 20 years ago. Count on it. We’ll be there, and we can help.

At first, it seemed like a dream. It was so new and it felt so good. Little did I know I was experiencing the beginning of a manic episode. I purchased a timeshare (not even knowing what one was) believing that this was the beginning of a whole new life for my fiancé and me. I received a phone call that day saying that I had been selected for a free trip to Las Vegas. I started to believe my dream of traveling the world would become a reality. The dream continued with beliefs that I was climbing the corporate ladder and a CEO job was within reach. So money was of no object. I had a calling from high powers to help those in need. The mail arrived with a solicitation from a non-profit health organization and I donated $200. My impaired judgment soon led me to the ATM, giving pan-handlers twenty dollar bills.

Once the euphoria went away, my mind raced until the thoughts made me so paranoid that my dream world turned to frightful delusions of a conspiracy. My grandiose thinking was replaced by screaming and crying for help. My family could not understand what had happened to the fiscally responsible, athletic woman who won top awards in her corporate sales career and traveled through New Zealand and Australia on her own after college.

Having finally had a manic break, I received a screening from my father's psychiatrist (my father also has bipolar disorder) and remained off work for over three months to endure the depression that followed. With only three months before my scheduled wedding date, my engagement ended, in part because of a lack of understanding from my fiancé.

Like many people who get a diagnosis of bipolar disorder, I wasn’t convinced I had the illness. How could someone as “normal” as I was have bipolar disorder? I now know the illness affects anyone; it does not discriminate.

I stopped my medication on my own and landed in a psychiatric hospital for 14 days. With my second leave from work, I became extremely discouraged about my own independence and whether or not I would be able to live on my own or return to my career. I felt ashamed. I lost hope.

But, after my hospital stay, not accepting my illness was not an option. I read as much as I could about bipolar disorder and started attending a DBSA support group. I will never forget the comfort I felt in a room filled with others who had walked in my shoes. In January 2004 I started my own local DBSA chapter, Tri-Valley Bipolar Support Group, in Pleasanton, CA.

Today, I continue to work as a sales representative and enjoy spending time with my friends and family in the Bay Area. I am living on my own in a townhouse I purchased last year. Knowing my triggers and how to effectively manage myself keeps me healthy and leading a productive, fulfilling life.
Leading the Way — A DBSA Fundraiser

DBSA is proud to invite you to Leading the Way! Please help us provide the most effective, practical and comprehensive training to DBSA chapter leaders. Money raised will help sustain the Chapter Leadership Forum held each year at the conferences.

Our more than 400 chapters are the heart of DBSA, running more than 1,000 support groups across the country. The assistance they offer is often life-saving and always encouraging. By purchasing a ticket, you will help DBSA chapter leaders learn new skills, become better facilitators and expand the services they offer to those in need.

As DBSA celebrates our 20th anniversary, we look back on many advances in the treatment and understanding of mood disorders. But we also look ahead at what still needs to be done.

For many of us, the cost of treatment makes it almost impossible to get the right care. Until insurance parity (equal coverage for mental health conditions) is passed into law, we are treated as second class citizens whose illnesses are not covered equally under our (often costly) insurance policies. Our illness is as real and as devastating as other illnesses; and we need, expect, and demand the same kind of help that is given to those with any other chronic illness.

The United States federal government has yet to pass parity legislation. While we continue to write to our legislators in Congress, there is something else we can do: work for parity at the state level. Many DBSA members have enacted successful parity campaigns in their states. DBSA Board member Randy Revelle was instrumental in getting mental health parity enacted into law in Washington state.

What can you do?
Get the facts. Find out:
- Your state’s mental health parity status. Many states have some form of parity in place, but there are restrictions, such as diagnoses covered or the size of the workplace (small employers are often exempt). Only Maryland, Minnesota, Vermont and Connecticut have laws providing complete parity. More information is available at www.nmha.org/state/parity/index.cfm.

- The names and contact information of your state Senators. Visit capwiz.com/ndmda/home/, DBSA’s Legislative Action Center and scroll down to “State Officials.”

- The economic benefits of parity. A law that keeps people healthy saves money. People with access to preventive care are less likely to face crisis situations and costly treatments. Visit www.mentalhealth.samhsa.gov for statistics.

Strength in numbers.
- Contact others who can help, support, and inform you. This includes your local DBSA group, your local mental health association (MHA) or your state protection and advocacy organization. (Visit www.napas.org or call 202-408-9514 for information.)

- If you are organizing a statewide parity campaign, you might also be able to get help and endorsement from community leaders and local businesses.

Start with small steps:
- Educate people about mood disorders.
- Write to your state legislators, as well as your local news media. Remind them that mental illnesses are real and treatable, and that insurance parity is the right of every American.

You can make an impact. For those of you who have ever heard DBSA President Lydia Lewis speak, you know that one personal story can change minds and hearts. Even if you’re not ready to tell your story, don’t be afraid to speak up, because you are not working alone. Mental health policy change can only happen through the combined efforts of all of us. Join us – together we can improve the lives of people living with mood disorders!
Every year, the Depression and Bipolar Support Alliance presents the Gerald L. Klerman Awards, the highest recognition given by DBSA. The awards are named after one of DBSA’s earliest supporters and a pioneer in mood disorder studies. They recognize researchers who have shown excellence in scientific achievement and made substantial contributions to furthering knowledge of the causes, diagnosis and treatment of depression and bipolar disorder.

This year Maria A. Oquendo, M.D., was selected to receive the Young Investigator Award. Dr. Oquendo is Clinical Professor of Psychiatry at the College of Physicians and Surgeons at Columbia University. Her contributions have brought attention to the presentation of psychiatric disorders in the Latino population in the U.S. However, she is best known for her studies of suicide. Dr. Oquendo is currently conducting the first randomized clinical trial focused on prevention of suicide in this country.

The Gerald L. Klerman Senior Research Award is given to an investigator who has made a lifetime contribution to furthering understanding of the causes, diagnosis and treatment of mood disorders. The Klerman Senior Research Award is DBSA’s highest honor.

This year, the Senior Research award was given to Paul E. Keck, Jr., M.D. Dr. Keck is Professor and Vice Chairman for Research at The Department of Psychiatry, University of Cincinnati College of Medicine. He has pioneered in the development of virtually every new pharmacologic treatment for bipolar disorder. He was a lead author of the 2004 Expert Consensus Guideline series on bipolar disorder treatment. He has also worked to enhance research infrastructure and psychiatric education by fostering collaboration among academic institutions.

Dr. Keck has been a strong supporter of DBSA since joining our Scientific Advisory Board in 1998. He served as Vice Chair from 1998–2001, and is active in DBSA at the local level by lending his expertise to DBSA Cincinnati.

I was honored to present these awards during the American Psychiatric Association’s Annual Meeting this May. We also were pleased to begin our year-long celebration of DBSA’s 20th Anniversary.

I am proud to lead the Scientific Advisory Board of this exemplary organization. With each passing year, DBSA enables more and more people to find help, hope, and support, and continues to work against misunderstanding and stigma. We look forward to the next 20 years of education, advocacy, and new hope through research and peer-to-peer support.

Scientific Advisory Board Update

Highest Honors

Ellen Frank, Ph.D.
SAB Chair

* More efficient use of resources to care for children while allowing them to stay with their families.

* Increasing the availability of home and community-based services and improving collaboration among agencies that serve children with mental health needs, including education, child welfare and juvenile justice.

You can help. Write your legislators today and tell them to support and pass The Keeping Families Together Act.

DBSA has placed sample letters in the Legislative Action Center for you to send to your legislators. Just visit the web site below. It only takes a few minutes but will help thousands of families.

www.DBSAlliance.org/Advocacy/Capwiz.html

Custody or Care?

No loving parent should have to give up custody of a child because the child has a mental illness. But every year thousands of families are forced to do so when they can’t afford the necessary mental health services. The latest figures show that parents placed more than 12,700 children into the child welfare or juvenile justice systems so they could receive treatment. It is a national tragedy that children who need emotional support the most must leave their homes to live with strangers.

When families are uninsured or have exhausted their private insurance benefits, mental health providers and public child welfare agency staff often advise parents that giving up custody is the only way to obtain services. Often, parents are told to call the police and turn their children over to the juvenile justice system to get mental health care.

Staying Together

Help may soon be available. The Keeping Families Together Act (H.R. 823 and S. 380) has been introduced to Congress. The bill’s main components include:

* Allocation of funds to improve access to state mental health and support services for families in danger of losing their children because they cannot afford mental health care.

* Amending the Social Security Act to permit the use of the Medicaid services waiver to allow states to move children out of inpatient psychiatric hospitals and into less restrictive home and community-based care.

* Creation of state interagency systems of care as an alternative to custody relinquishment.

www.DBSAlliance.org/Advocacy/Capwiz.html
Road to Recovery

A mental health conference designed with YOU in mind!

This conference is for you!
Whether you or someone you love are newly diagnosed or have been managing depression or bipolar disorder for years, increasing knowledge and gaining tools to work towards recovery are keys to a healthy life.

Illinois
Stephens Convention Center
Rosemont, IL
Saturday, August 27

New Jersey
Hanover Marriott
Whippany, NJ
Saturday, September 10

Texas
Fort Worth Plaza Hotel
Fort Worth, TX
Saturday, October 8

Breakout sessions include:
- Wellness Strategies
- Taking an Active Role in Your Treatment
- Mental Health Treatment for Children
- Advocacy In Action
- Helping a Family Member or Friend

Speakers include:
- Andy Behrman, author of Electroboy: A Memoir of Mania
- Peter Ashenden, Executive Director of the Mental Health Empowerment Project, Inc.
- Jan Fawcett, MD, co-author of New Hope for People with Bipolar Disorder

Registration starts as low as $55!

Visit www.DBSAlliance.org or call (800) 826-3632 for more information or to register!

HOPE • HELP • SUPPORT Wristbands Now Available!

DBSA has created blue and yellow mood disorder awareness wristbands with the inspirational words HOPE, HELP and SUPPORT subtly embossed, along with the DBSA logo.

Buy several of these awareness wristbands to show there is hope through education and research, help eliminate stigma, and support people living with depression and bipolar disorder. They also remind you what to do when you're in a difficult place: hold on to hope, get help from family, friends and health professionals, and seek support from peers who have been there.

Mood disorder awareness wristbands are $3 each. Visit www.DBSAlliance.org or call (800) 826-3632 to order yours today!

Change for Change: Together we can make amazing things happen

Change for Change is a fundraiser started by DBSA in 2003 to support our programs and services. You can help by collecting spare change and dollar bills from your pockets or purse at the end of each day.

Bring your change with you to DBSA's Illinois, New Jersey or Texas conference (or count the change and write a check payable to DBSA) where it will go a long way toward providing help, hope and support.

Whether large or small, your contribution assists us in reaching people through our support groups, website, publications, and toll-free information line. If you aren't able to attend the conferences, you can mail a check or change to DBSA's Chicago office.

Contact DBSA to receive Change for Change bags to share with family, friends, co-workers and fellow support group members. E-mail giving@DBSAlliance.org or call (800) 826-3632. Thank you!
Teen Initiative in Colorado Springs
DBSA Colorado Springs’ Teen Depression Initiative has helped over 2,000 teens recognize the signs of depression and suicide, and understand the importance of early intervention. Since 1999, the Colorado Springs chapter has reached out to local high schools by enlisting five young adults to educate students on depression and suicide. These young volunteers tell their stories in their own words and help the students understand mood disorders. The initiative has received glowing reviews from students:

“Thank you for coming to our health class. We learned a lot about bipolar and depression. For example, I didn’t know that depression is actually a disease. I also thought that it could be cured by willpower. I learned that this is not true. Before you came, I didn’t know what bipolar meant.”

“I just wanted to say thank you so much for coming in, after our discussion you both made me realize what it was that my dad was suffering from, and now I will have a resource where I can get him help.”

DBSA Colorado Springs can be reached for more information on this and other programs by contacting Karen Fallahi at DBSA.cs@pcisys.net or (719) 477-1515.

A Rainbow of Feelings
Cheryl Murphy, chapter leader with DBSA Southern Nevada worked in a creative way this spring to fight stigma surrounding mental illness in adolescents. A four part play written to address that stigma, “A Rainbow of Feelings,” was performed by a local theatre company in Las Vegas that incorporates parents and children with mental illnesses into its cast.

“We want to help eliminate the stigma associated with mental illness. Our kids suffer the most. They may be ostracized at school, or they don’t socialize. This program gets the kids involved in the arts, so they can put a lot of their negative energy into a positive thing. This was a vision and a dream I’ve had since my daughter was diagnosed with bipolar disorder,” Murphy said.

DBSA Southern Nevada can be reached for more information by contacting Cheryl Murphy at DBSA.southernnevada@yahoo.com or (702) 255-4003.

Act Now to Offer Help, Hope and Support in Your Community!
Throughout the United States, at least 25 million individuals live with mood disorders. The need for education, understanding, and support is growing. DBSA chapters and support groups can provide that support. Currently, there are approximately 400 chapters nationwide operating over 1,000 DBSA support groups. We need your help to make help, hope and support available in your community!

As independent affiliates of DBSA, local chapters’ main purpose is to provide peer-run support group meetings in their communities. These meetings are open to the public, free of charge, and offer a confidential and supportive environment to share experiences with others who have been there and understand the journey. Choosing to start a chapter and support group:

- Creates a network of people concerned about and working on the same issues.
- Brings together the collective wisdom of people who have already experienced the same challenges for which you are seeking solutions.
- Creates a group that can make a difference in your community, maybe even save a life.
- Offers the patient’s perspective to legislators and the local medical community.

Starting a chapter is an easy process. There are a number of resources to help you along the way, including DBSA’s

Chapter Start-Up Guide, chapter staff, and current chapter leaders. The Chapter Start-Up Guide explains more about DBSA as an organization, breaks down the steps of starting a support group, details the benefits of being affiliated with DBSA, and includes the application to affiliate your support group. Conversations with staff and chapter leaders will help answer any questions or concerns you may have and brainstorm ideas and resources in your area.

Once the chapter has been established, your DBSA affiliation can help you to successfully grow the chapter. Benefits of affiliation include free copies of DBSA brochures and videotapes, leadership training opportunities through regional or national meetings, on-line learning tools, and a Chapter Leadership Guide.

While the primary participants in the chapters and support groups are people diagnosed with depression or bipolar disorder, friends and family members are also encouraged to get involved in creating a network of support.

Please contact the Chapter Relations Department (800) 826-3632, x153, or via e-mail at chapters@DBSAAlliance.org to start a chapter today!

New Chapters
Call (800) 826-3632 or visit DBSA’s web site for group contact information.

U.S.
- DBSA Nashamah (AL)
- DBSA Conejo Valley (CA)
- DBSA Stuart (FL)
- DBSA North Georgia (GA)
- DBSA Loganville/Snellville (GA)
- DBSA Rockdale County (GA)
- DBSA McHenry County (IL)
- DBSA Hope – Belvidere (IL)
- DBSA Hope – Oregon (IL)
- DBSA Southbridge – Sturbridge (MA)
- DBSA Greater New Bedford (MA)
- DBSA Oak Island (NC)
- DBSA Long Beach Island (NJ)
- DBSA Newark (NJ)
- DBSA South Jersey (NJ)
- DBSA West Columbia (SC)
- DBSA Anderson County (TX)

International
- DBSA Ridge Meadows (Canada)
A funny thing happened on the way to the office one crisp September morning several years ago. A fellow chapter member and friend suggested that I would be a good candidate to be screened for a documentary: “Real Men. Real Depression.”* I decided to give it a try.

In mid-October, the film crew came to my house. They came on a day when I was bitten by the “black dog of depression.” To my chagrin, my moods can be mercurial. In clinical terms, I have rapid cycling bipolar disorder. One of the real benefits of being a member of this organization for many years is my ability to be open and honest about my illness. I spent the next two hours responding to unscripted questions. Surprisingly, thoughts and feelings rolled freely out of my mouth. As I began to relive my depressions, my eyes welled up. I wasn’t giving a third person narrative; I was in the eye of my personal storm.

Months later, I was notified that they wanted to use my interviews. These spots were distributed to major media networks in May 2003 as Public Service Announcements (PSAs). In addition, there have been full page ads in physicians’ journals (especially targeting primary care physicians), men’s health, sports and general weekly periodicals. How shocked I was to see a full page color photo of myself in a national health magazine!

To this day, I continue to see my likeness in other periodicals in efforts to reach out to a drastically underserved population—men with depression. Studies have consistently shown that men are half as likely to have depression as women; however, some researchers estimate that men are less likely than women to recognize, acknowledge and seek treatment for their depression. And men die by suicide at four times the rate of women.

These statistics don’t tell us how many men struggling with depression neither seek help nor report their depression to anyone, anywhere. If any number of men will travel aimlessly for miles rather than ask someone for directions, think how difficult it will be for these same men to ask for help with their mood disorder.

It is my hope that this campaign and my participation in it will make the intolerable tolerable, and the unacceptable acceptable. Had I not been a several-year member of MDDA-Boston, not only may I have not come forward to represent other men, I may not have come forward to represent myself.

* Sponsored by the National Institute of Mental Health (NIMH).

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**Wellness Tips**

1. **Support groups** are safe, welcoming, confidential, understanding gatherings. Visit www.DBSAlliance.org to find a group near you.
2. **Music** has the power to help us calm down or motivate, whether we are listening or performing.
3. **Healthy eating.** Avoiding fats, sugars, cholesterol and salt; drinking water and balancing our food groups can help improve mood.
4. **Exercise/walking/movement** can get us through depression or use up extra energy if mania seems close at hand.
5. **Pet therapy.** Our pets offer us unconditional love, a shoulder to cry on when needed, and they never get tired of us.
6. **Journaling.** Setting aside time each day to think through what has occurred and write about it can help us look for patterns and better understand ourselves.
7. **Sleep.** It's impossible to overestimate how important regular sleep and wake times can be for people living with mood disorders.
8. **Creative writing and poetry** allow us to process information in artistic ways that can be healing and safe.
9. **Meditation** can help us become more calm and focused. It isn't complicated; just sit quietly and do your best to clear your mind. It gets easier with practice.
10. **Arts and crafts** can help us explore issues non-verbally. Pick your favorite and try it out. Don’t worry about the end result.
11. **Mood tracking.** Taking 60 seconds a day to track our moods can alert us of problems earlier and help us address them.
12. **Friends and family** can be our shelter from the storm.
13. **Work.** Having a job that forces us to get out of bed every day helps our self-esteem and self-discipline.
14. **Education** about our illness empowers us to make decisions with our health care providers, so we can say, “Don’t work on me, work with me”.
15. **Spirituality.** Belief in and reliance on something more powerful than yourself is an important aspect of wellness for many people.
16. **Volunteering.** Whether you are working or not, adding a volunteer job helps you to give back as a part of your recovery journey.
17. **Yoga.** Combining the benefits of exercise and mediation, yoga is a beneficial wellness tool for many.
18. **No drinking/substance use.** Getting clean and/or sober can work wonders on your moods and treatment effectiveness.
19. **Gardening.** The combination of exercise, beauty and being outdoors makes this wellness strategy irresistible to many of us.
20. **Tracking triggers** (predictable actions or situations that destabilize moods) and preparing for them can help us avoid severe mood episodes.
DBSA Outreach is a quarterly publication serving supporters and constituents of the organization. DBSA does not endorse or recommend the use of any specific treatment or medication. For advice about specific treatments or medications, patients should consult their health care providers.

**Editor:** Laura Hoofnagle

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**Support DBSA!**

Just your gift alone will make a difference. Your gift alone will change a life. It may even save one. Contribute to DBSA by using this form, calling us at (800) 826-3632 or visiting our secure website at www.DBSAlliance.org. All information provided is held in strict confidence. If you have any questions, please call (800) 826-3632 or (312) 642-0049.

**Thank you for your gift!**

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**Yes, I want to make a difference. Enclosed is my gift of:**

- $500 Gold
- $150 Silver
- $50 Bronze
- $20 Member
- Other $ ________

**Name** ________________________________________________________________________________________________

**Address** ___________________________________________________________ **City** ___________________________________________

**State/Province** ____________________________ **Country** ____________________________ **Zip/Postal Code** ____________________________

**Daytime Telephone** ____________________________ **E-mail** _________________________________________________________

- Check (payable to DBSA)
- Money order
- Mastercard
- Visa
- Discover
- American Express

**Account Number** ____________________________ **Exp. Date** ____________________________

- I’d like details on including DBSA in my will.
- I wish my gift to remain anonymous.
- I have enclosed my company’s matching gift form.
- Please send me more information on mood disorders.
- Please send me _____ donation envelopes to share.
- Please send all correspondence in a confidential envelope.

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**To make a recurring donation or pledge, visit www.DBSAlliance.org/gifttypes.html**

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**If you would like to make your gift a Memorial or Honorary tribute, please complete the following:**

- In memory of / In honor of (circle one)

**Name** ____________________________________________________________________________

**Address** ____________________________________________________________________________

**City, State, Zip** ______________________________________________________________________

Please send this form and payment, using the envelope in the center of Outreach, to: DBSA, 730 N. Franklin St., Suite 501, Chicago, IL 60610-7224 USA.

Credit card payments may be faxed to (312) 642-7243.