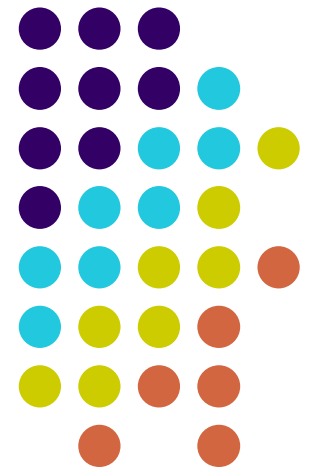


# DBSA

## *The Power of Peers*

Allen Doederlein, DBSA President  
Lucinda Jewell, Ed. M., DBSA Chair  
Christy Beckmann, DBSA Treasurer



Depression and Bipolar  
Support Alliance

# DBSA



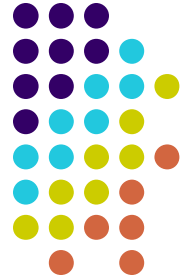
*What makes DBSA unique? DBSA's tag line, "We've been there. We can help." is far more than a catchy slogan. DBSA is led by and created for individuals living with mood disorders...and that experience informs everything that we do.*

## DBSA is

- Peer-led: 50%+ of staff and board members live with a mood disorder and all DBSA support groups are facilitated by peers
- Targeted: focuses solely on depression and bipolar disorder
- Nationally recognized: our peer specialist training services are acknowledged as some of the best in the nation—one of six curricula approved for use by the US Department of Veterans Affairs
- Innovative: offering leading-edge interactive online resources
- Wellness-centered: informing, empowering, supporting, and inspiring individuals to achieve the healthy lives they want to lead



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# DBSA PRESENTATION

Information and best practices...to inform international efforts in patient advocacy

- **Mental Health NOW**  
*Lucinda Jewell*
- **The Role of Family Support in Advocacy**  
*Christy Beckmann*
- **Establishing Peer-led Support Groups**  
*Allen Doederlein*

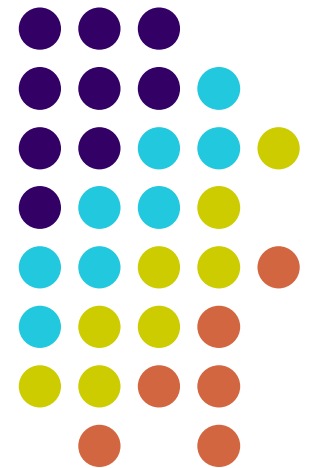


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# Mental Health NOW

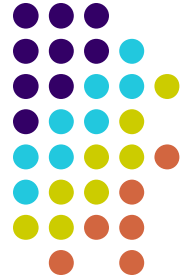
## *Bringing Wellness to Neurodiversity*

Lucinda Jewell, Ed. M.  
Chair  
DBSA National Board of Directors



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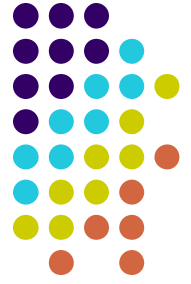
# WHO?



- **Someone you know:** At least 450,000,000 people in the world live with a mental health condition—rich, middleclass and poor, artists, teachers, students, scientists and politicians—your family and friends.
- Even without modern diagnostics and treatment for depression, **Abraham Lincoln** served as President of the United States and **Winston Churchill** as Prime Minister of England.



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# WHEN?

- Presently, the public view of psychiatric disorders is preoccupied with despair, danger and drain.
- Little media attention is paid to acknowledging those who contribute to the social good in spite of, or because of, living with a mental health condition.



# WHERE?

## The stats you know:

- **Depression** is the **no. 1** disease factor and **15%** of the burden of illness in developed countries—**more than all cancers combined.** (WHO)
- **26.2%** of the U.S. has a mental health condition. (NIMH)
- **Suicide** is the **no. 2 killer** of **25-34 year-old** Americans, and the **no. 3 killer** for **10-24 year-olds.** (CDC)
- **WORLDWIDE, depression** appears in the top ten disease factors and is **on the rise.** (WHO)



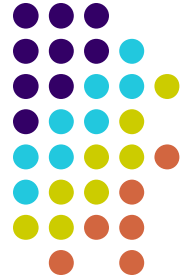
# HOW?



- Largely missing is the recognition that many people successfully manage their mental health issues.
- How would healthcare protocols and delivery be impacted?
- How would people with mental health conditions be seen and how would they see themselves?



# NOW



- **Value** people living with mood disorders: The conditions are not who we are but how we temporarily feel, even as they have shaped and influenced our lives.
- 
- **Validate**: No matter how we feel, we matter and make a difference in the world.
- **Invest** in quality of life and wellness issues aligned as a single community—**partners** in mental health and wellbeing.
- **Worldwide**: it will take continued political will for holistic approaches to mental health management to become standard.



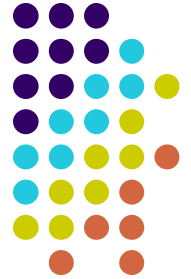
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# WHAT WOULD BE POSSIBLE?



- if mental health conditions were viewed as neurodiversity that requires effective management for responsible use?
- if mental health conditions were viewed as a necessary process of brain evolution rather than pathology?

# MENTAL HEALTH NOW



- Mood disorders are manageable, like diabetes, and wellness is possible.
- PROCOVERY—proactive, present-based practices for wellness.
- Transform the conversation for mental health—**Speak out, come out, stand up, speak up. Together we can.**



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# JUST TO NAME A FEW

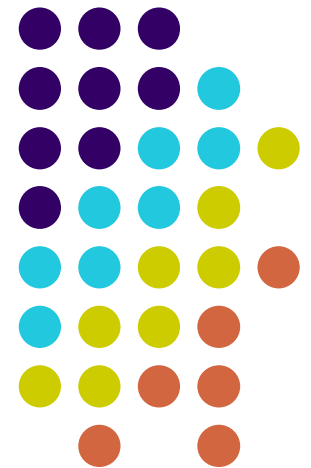
Buzz Aldrin—U.S. astronaut  
Parven Babi—Bollywood actress  
Kjell Magne Bondevik—Former P.M. of Norway  
Tim Burton—English director  
Stephen Fry—English actor  
Kay Redfield Jamison—U.S. scientist/writer  
Primo Levi—Italian scientist/writer  
Sinéad O'Connor—Irish singer  
Graeme Obree—Scottish cyclist  
Philip Roth—U.S. writer  
Jim Salinger—N.Z. climate change scientist  
Michael Slater—Australian cricketer  
Stuart Sutherland—English psychologist  
Ted Turner—U.S. media mogul  
J. Craig Venter—U.S. genome maverick



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# The Role of Family Support in Advocacy

**Christy Beckmann**  
Immediate Past Chair, Treasurer  
DBSA National Board of Directors



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# The Role of Family Support in Advocacy



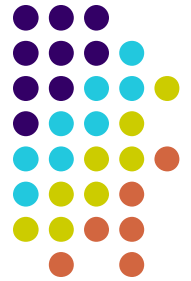
Clinical professionals have limited contact with families, leaving families and friends with unmet needs and less able to be helpful for the recovery of their family member.

Family and caregiver support groups meet this need and also advance advocacy.



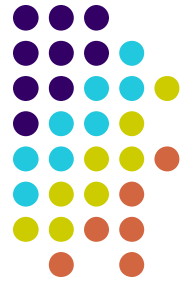
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# The goal of family and friends support groups is to:



- Improve empowerment, knowledge and emotion-focused coping of family members.
- Reduce the anxiety and possibly depression experienced by family members and friends.
- Improve the functioning of family members with respect to problem solving skills.
- Provide communication skills so that if non-recovery behavior presents, family and friends have communication options.

# What do family and friends support groups do?

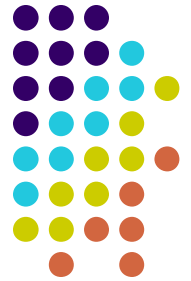


- Offer the lived experience of a person with a mood disorder; provide empathy.
- Offer a safe place for self-disclosure for family and friends.
- Share techniques for problem solving, empathetic listening, and communication.
- Share personal information about medications, side effects, and strategies for medication adherence.
- Offer information related to brain disorders and the most effective evidence-based treatment options that promote recovery.





# What do family and friends support groups do?



- Acquire strategies for handling crisis and relapse.
- Focus on the caregiver's coping skills for worry, stress, and emotional overload.
- Identify support and services within the community.
- Provide information on advocacy to improve and expand services.
- Help family and friends cope with fears.



# Are family support groups effective?



**YES.**

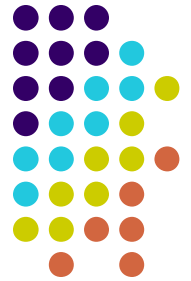
Study funded by the USA National Institute of Mental Health, University of Maryland School of Medicine Study 2006—2009, showed that compared to control group\*

- Reduced stress of participants.
- Significantly greater empowerment of family and friends.
- Significantly improved knowledge and information about mental health.
- Significantly reduced worry.
- Reduced anxiety and distress.
- Improved family system functioning.

\*Based on FAD problem solving and COPE acceptance scales



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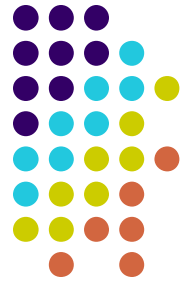


# What else does this mean?

## Fit Also with Qualitative Study

- The benefits are understandable in terms of self-help theory, stress/coping and trauma/recovery models.
- Suggests that new info+support+skills=changes in awareness, more active coping, increased empowerment
- Which helps reduce distress, improve family relating, and leads to broader benefits.

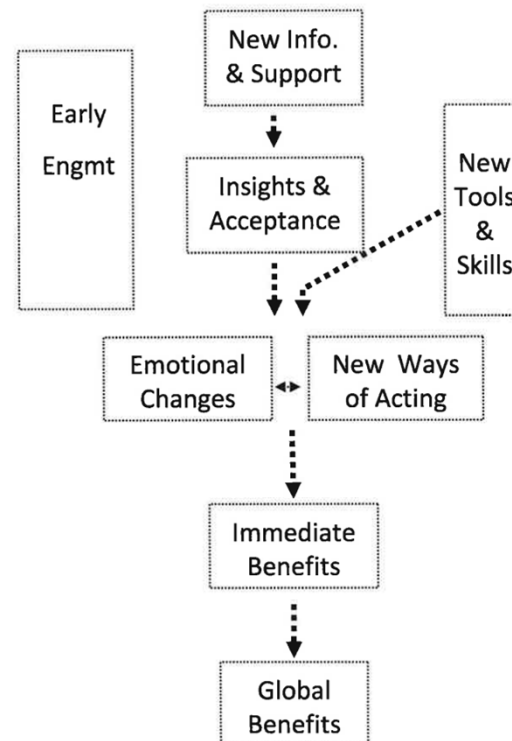
# What else does this mean?



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Lucksted, Stewart, Forbes, 2008



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Lucksted, Stewart, Forbes, 2008



# Some Conclusions

- Evidence shows that peer family interventions enhance family outcomes.
- Peer-lead family programs are important in the tool kit to help families of people with mental health diagnoses.
- Families and friends are excellent advocates.

# What are some resources?



- Depression and Bipolar Support Alliance
- Mood Disorders Association of Canada
- Canadian Mental Health Association
- Community Resource Connections of Toronto: [www.crct.org](http://www.crct.org)
- Depression Alliance of the UK
- [www.FamilyAware.org](http://www.FamilyAware.org)
- [www.MayoClinic.com/health/depression](http://www.MayoClinic.com/health/depression)
- Mental Health America: [www.nmha.org](http://www.nmha.org)
- National Alliance on Mental Illness: [www.nami.org](http://www.nami.org)



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# What are some resources?

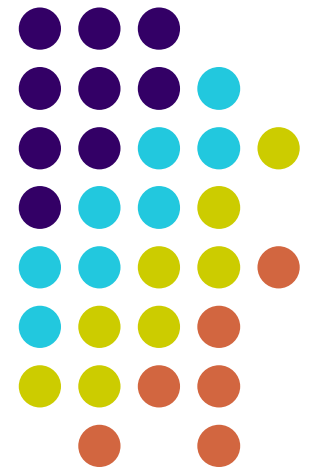


- SAMHSA Consumer-Operated Evidence-Based Practice Kit  
*Guide provides tools for developing mental health services owned & run by people in recovery*
- National Mental Health Consumers' Self-Help Clearinghouse  
"Starting a Self-Help/Advocacy Group"
- "Stepping Up: A social inclusion action plan for mental health reform 2007-2012"  
*Report from South Australia's Social Inclusion Board, plan for transforming the mental health system, emphasis on family, peers, and friends*



# Establishing Peer-led Support Groups: The DBSA Model

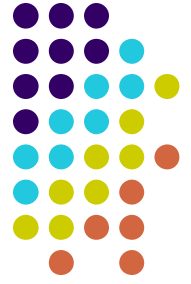
Allen Doederlein  
President  
DBSA



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# WHY ATTEND A DBSA SUPPORT GROUP?



**DBSA support groups provide the kind of sharing and caring that is crucial for a lifetime of wellness.**

**“The members of my DBSA support group reached out to me and made me realize that I was not alone. If not for the support that I received from this organization, I probably wouldn’t be here.”**

— DBSA support group participant

**“I think the reason I was depressed for so long was that I felt excluded from everything, even my family. Finding people who accept you for who you are—I can’t put a price tag on that.”**

— DBSA support group participant



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## DBSA support group participants say that their DBSA groups\*

- Provide a safe and welcoming forum for mutual acceptance, understanding, and self-discovery
- Give them the opportunity to reach out to others and benefit from the experience of those who have “been there”
- Motivate them to follow their treatment plans
- Help them understand that mood disorders do not define who they are
- Help them rediscover strengths and humor they may have thought they had lost

*\*2000 DBSA support group survey of 2,049 people from 190 cities in 38 states and the District of Columbia*



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## What benefits do DBSA support groups offer?

Benefits	# of participants benefiting to some or great extent
➤ Provide interpersonal support	98.2%
➤ Help to cope with problems/crises	96.7%
➤ Help to make better decisions	95.1%
➤ Help to understand medications/treatment	93.7%

*\*2000 DBSA support group survey of 2,049 people from 190 cities in 38 states and the District of Columbia*



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## How can DBSA support groups help people maintain better mental health?

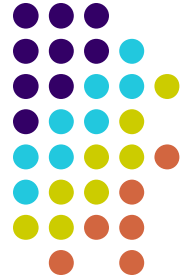
- People who had been attending a DBSA group for more than a year were less likely to have been hospitalized in the past 12 months.
- The longer people had attended a DBSA group, the less likely they were to have stopped medication against medical advice, and the fewer barriers to following their treatment plan they experienced.
- More than half of the people who were not following their treatment plans when they began attending their DBSA groups became more motivated to do so over time with continued group attendance

*\*2000 DBSA support group survey of 2,049 people from 190 cities in 38 states and the District of Columbia*



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# 6 key elements of a DBSA chapter's support group

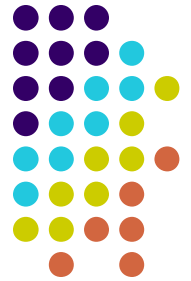


1. Peer-led
2. Focus on self-help
3. Safe & accepting
4. Confidential
5. Meet regularly
6. Free of charge



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# DBSA chapters' support groups are *adjunctive*



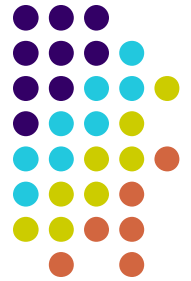
They are NOT

1. Therapy or treatment
2. A place to diagnose or a substitute for professional care
3. A 12-step group
4. A “pity party”
5. An expert giving a lecture



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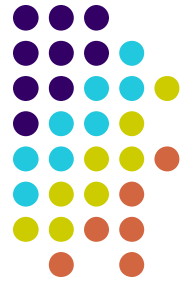
# What does a person with a mood disorder need to start a support group?



1. A commitment to peer support
2. Support of other people with mood disorders and family members/friends
3. Meeting location
4. Telephone number and email address
5. Professional support from a local advisor
6. Responsibility to yourself



# What does a clinician need to help her or his patient start a support group?



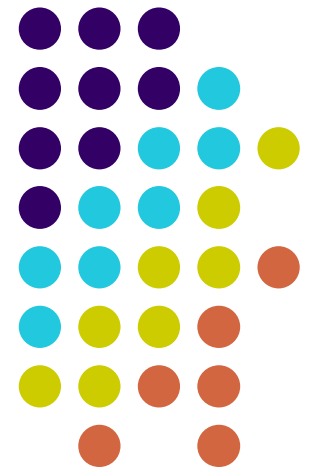
1. A belief in peer support
2. An interested patient
3. Ability to help with a meeting location
4. Willingness to provide support as a professional advisor
5. Responsibility to your patients
6. Responsibility to yourself



# DBSA

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# 10TH INTERNATIONAL CONFERENCE ON BIPOLAR DISORDERS

A Meeting of the International Society for Bipolar Disorders



**June 13-16, 2013**

**Loews Miami Beach**

**Miami Beach, Florida**

## Important Dates – July 2012

- Symposia & Concurrent Session Applications Open
- Rapid Communications & Poster Presentation Proposal Applications Open
- Lilly Young Investigator Fellowship in Bipolar Disorder Applications Open

**[www.10thbipolar.org](http://www.10thbipolar.org)**