BEYOND DIAGNOSIS: DEPRESSION AND TREATMENT

A Call to Action to the Primary Care Community and People with Depression

NATIONAL DMDA

National Depressive and Manic-Depressive Association
730 North Franklin Street, Suite 501
Chicago, Illinois 60610-7204 USA
www.ndmda.org
(800) 826-3632

Call to Action

Improve Communication Between Primary Care Physicians and Patients Being Treated for Major Depression & Increase Patient Involvement in Antidepressant Treatment Decisions

The National Depressive and Manic-Depressive Association (National DMDA), a patient advocacy organization, calls upon the primary care community to move beyond the diagnosis of depression and increase patient involvement to improve the quality of care for people being treated for depression in the primary care setting.

This Call to Action is based on the results of a comprehensive study of people being treated for major depression in the primary care setting and of primary care physicians. Conducted by National DMDA, the survey, *Beyond Diagnosis: A Landmark Survey of Depression and Treatment*, provides compelling evidence of a critical patient/physician communication gap, particularly relating to treatment decisions and disclosure of side effects.

The survey confirmed that a significant percentage of people with depression are diagnosed and treated for long periods of time by primary care physicians, and that the only health care professional the majority of patients talk to about the treatment of their depression is their primary care physician. In addition, the results indicate that while primary care physicians are routinely involved in the treatment of depression, and overwhelmingly rely on antidepressants as the treatment of choice, **a significant population of patients who require antidepressant therapy may be achieving less than the best possible treatment outcomes. Lack of compliance to antidepressant therapy, persistent or problematic side effects and suboptimal recovery are all consequences of this situation.**

In response to the pressing need to bridge the gap in patient/physician communication, National DMDA calls upon influential organizations representing primary care providers and mental health professionals to work together to:

- Raise awareness among primary care physicians that the communication dynamic with patients about depression and its treatment can positively affect patient compliance with therapy, as well as complete recovery and satisfaction with care.
- Join National DMDA in creating and implementing educational outreach programs to the primary care community and to patients that will improve communication and promote greater patient involvement in treatment decisions.

It is the position of National DMDA that:

- Treatment success should be measured by complete symptom relief, minimizing persistent or problematic side effects, and improvements in function. These factors should be assessed routinely throughout treatment. Physicians and patients need to work together throughout the course of treatment to improve the level of control that people can achieve.

- People on antidepressant therapy should not have to experience side effects so problematic that they stop taking their medication or skip doses.

- The patient/physician relationship needs to be strengthened to increase patient participation in treatment decisions at the time of diagnosis, when medication is prescribed and at agreed-upon intervals throughout the duration of treatment. This should include complete and open discussion of potential side effects.

- Physicians need to listen more closely to patients and their concerns, while at the same time confirm that patients understand what is being discussed. The patient should be encouraged and empowered to report concerns, and receive acknowledgement from the physician in return. Further, the physician should verify that the patient has understood treatment issues, limitations and medical recommendations. This type of exchange will enable the primary care physician to move the quality of treatment and the recovery process forward.

- Antidepressant choices should be based on all available treatments to ensure that the most appropriate regimen is prescribed to match the individual patient's needs. This will help each patient realize the best possible results: better management of symptoms, ability to avoid or address adverse side effects of antidepressants that may affect compliance, and increased satisfaction with treatment.

Rationale for the Call to Action

During the past few decades, much research and needed attention has been directed to improve the diagnosis of depression and initiation of treatment in the primary care setting. New classes of antidepressant medications were introduced offering potential advantages in dosing, reduced side effects and reduced risk of fatality due to overdose compared to older medications.[1-3] Simultaneously, a broad range of public awareness, policy and medical education efforts were initiated. These efforts have helped to reduce the stigma of depression, document the impact of the disease on individual suffering and societal costs, and encourage individuals to seek care for an often disparaged condition that is now considered to be a treatable medical illness.[4]

As a result, the number of people receiving a proper diagnosis continues to increase and the treatment of depression has become a significant responsibility for the primary care community. But, as more people are diagnosed, the need to improve treatment practices and to strengthen the physician/patient partnership becomes more pressing to ensure that patients receive the best care possible throughout the duration of treatment.

Therefore, National DMDA convened a meeting with representatives from the nation's leading and most influential primary care and mental health organizations to present the survey results, discuss the serious communication gap that exists, and explore ways to bridge this disconnect between patients and physicians.

Communication gap supports need to improve treatment practices

Patients surveyed report considerable experience with depression and antidepressant therapy.

Prior to treatment, patients report that depression caused limitations in many aspects of their lives. Three quarters (76%) said that depression limited them in sleeping, two thirds or more said that depression limited them in social activities (70%), lifestyle (69%) and family relationships (69%). More than half said that physical activities (62%) and work motivation (58%) were affected, and that depression had a negative effect on their relationship with a spouse or partner (52%).

The survey confirms that for many patients, depression is a chronic or recurring condition and that the primary care physician is virtually their only source of information about antidepressant therapy:

- On average, patients had first been prescribed an antidepressant 11.2 years earlier and 37% have had 4 to 20 or more episodes of depression, with another 21% who had 2 or 3 episodes. They have been taking their current antidepressant for three to five years.
- 84% say that they talk to no other health care professional about antidepressant side effects.

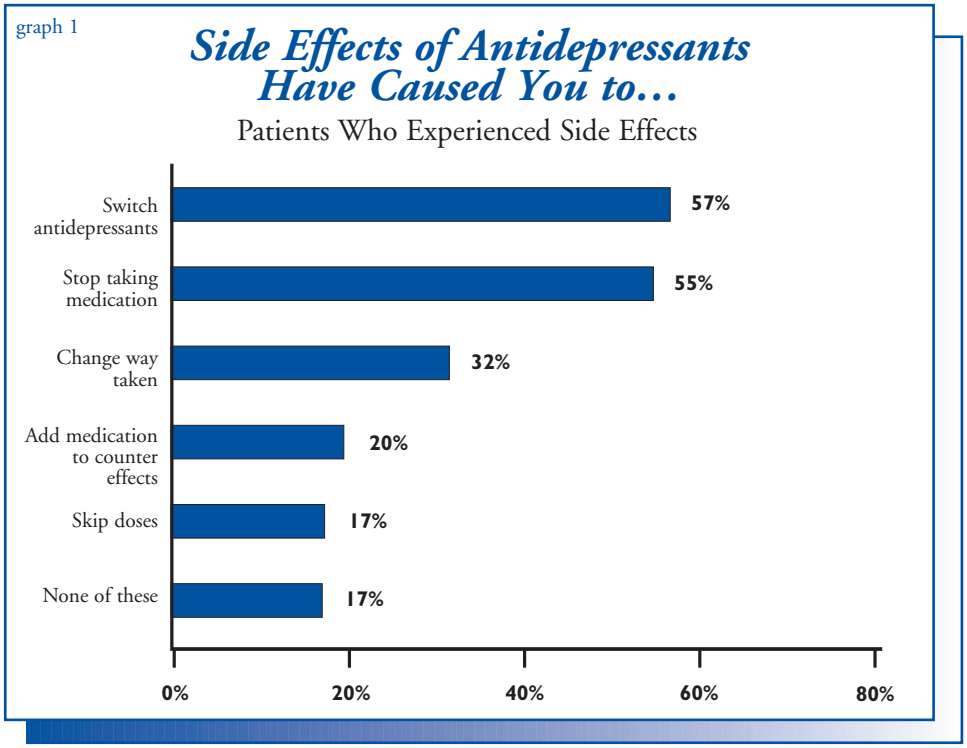
On the part of primary care physicians, the survey reveals that they treat depression mainly with antidepressants, and that the majority of their patients require long-term therapy:

- Almost all primary care physicians (97%) report they prescribe an antidepressant for patients with newly diagnosed major depression.
- Primary care physicians report that 60% of patients for whom they prescribe antidepressants will need long-term therapy, i.e., for a year or longer.

Yet even after years of therapy, many patients do not have their depression completely controlled, many have trouble complying with medication therapy because of problematic or persistent side effects, and many believe they have to tolerate side effects.

- Less than a quarter of patients say their depression has been completely controlled in the past two months, though they have been taking the same antidepressant for three to five years.
- Before treatment, the majority of patients reported that depression restricted several aspects of their lives, including sleeping (76%) and their sex life (59%). In a separate question, patients were asked to voluntarily identify improvements/positive effects of antidepressants. Overall, six out of seven (85%) patients being treated with an antidepressant for depression report that antidepressant medication has had a positive impact on their lives. However, significantly fewer mentioned improvements in specific areas such as sleeping (13%) or regained sex drive (3%).
- Nearly half of patients report having problems with medication side effects at some point; 15% report side effects from their current antidepressant, even after taking it for almost three years, on average.

graph 1



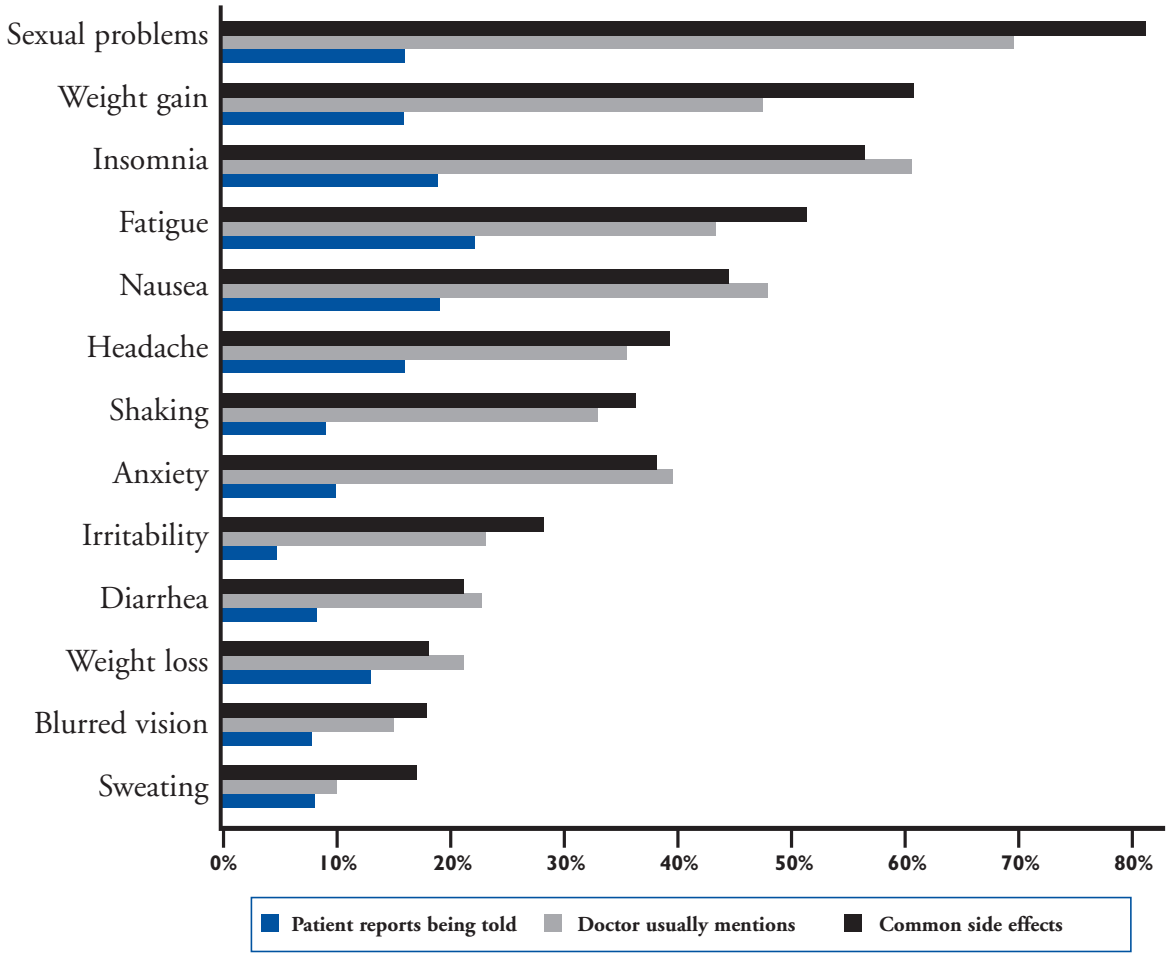
- Although almost all patients agreed that they should ask for another medication if side effects were intolerable (98%), those who had problems with side effects, in fact, were nearly as likely to stop taking the drug (55%) as to ask to switch to another antidepressant (57%). (Graph 1)
- Among the close to half of patients who reported having side effects, compliance was compromised due to those side effects: 55% had stopped taking an antidepressant, 17% had skipped doses. (Graph 1)

The survey also uncovers some hidden issues. Patients and primary care physicians express very different perceptions about treatment decisions and treatment side effects.

- 71% of primary care physicians say treatment decisions are made jointly with patients while substantially fewer patients (54%) say decisions were made this way. In a separate question about treatment decisions, just 36% of patients say their doctor had asked about their preferences or willingness to tolerate certain side effects before deciding which antidepressant to prescribe.
- For the most part, primary care physicians report they usually alert patients about common side effects such as sexual problems, insomnia, weight gain, nausea and fatigue. Most patients say they were not told about these side effects. (Graph 2)
  - 34% of patients say they were not told about any possible side effects.
  - Significantly fewer patients report that sexual problems (16%) or weight gain (16%) were mentioned, compared with physicians who say they usually mention these two side effects (69% and 47%, respectively). (Graph 2)
  - 60% of physicians say they usually mention insomnia to patients, but only 19% of patients say they were alerted about this. (Graph 2)
  - 47% of physicians respond that they inform patients about nausea, while only 19% of patients agree with this. (Graph 2)
- Physicians do not mention sexual problems, weight gain and fatigue as consistently as they recognize these as common side effects, while they are more consistent in both recognizing and mentioning other side effects. (Graph 2)
- Very few primary care physicians (9%) believe patients have to tolerate antidepressant side effects, compared with 40% of patients who believe they do.

graph 2

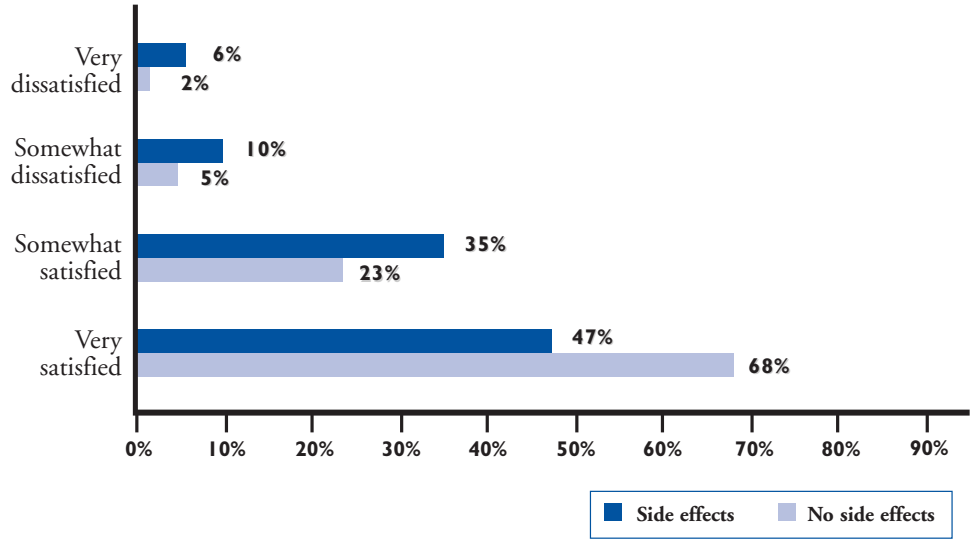
Common Side Effects Recognized by Doctors and Those Mentioned to Patients



graph 3

Satisfaction with Current Antidepressant Compared to Side Effects from Medication

Patients Being Treated for Depression



On the other hand, the proportion of patients who were satisfied with their treatment increased when patients understood the treatment issues that were discussed with their primary care physicians.

- 75% of patients who were very satisfied with their physician say they fully understand the issues.
- 31% of somewhat satisfied patients say they fully understand the issues.
- 18% of somewhat or very dissatisfied patients say they fully understand the issues.

In addition, the proportion of patients who were satisfied with their treatment increased when side effects were minimized. (Graph 3)

- Two thirds (68%) of those who had no side effects were very satisfied with their current antidepressant.
- Less than half (47%) of those who have had side effects were very satisfied with their current antidepressant.

The National DMDA survey involved telephone interviews with 1,001 people with major depression who currently take a single antidepressant prescribed by a primary care physician. The average age of the patient sample was 51, with women making up 84% of respondents. In addition, 881 practicing primary care physicians from the American Medical Association and the American Osteopathic Association specialty listings of practicing family physicians, general practitioners, and internal medicine physicians completed and returned an eight-page written questionnaire.

Ways to improve communication and effect change in treatment practices

For many of today's practicing physicians, the topic of diagnosing and treating depression and other mental illnesses was not a significant part, if any, of their medical training. Depression is admittedly one of the more complicated illnesses to treat. While there are validated assessment questionnaires for screening and measuring progress, there are no biologic or lab-based tools, making communication between the physician and the patient even more important in measuring a patient's progress. Furthermore, the current medical environment poses multiple challenges including time constraints and reimbursement limitations.

The survey supports the need for the primary care physician to factor in patients' unique needs and concerns when prescribing an appropriate antidepressant medication. The recent clinical guideline by the American College of Physicians-American Society of Internal Medicine (ACP-ASIM) concludes that all antidepressants are equally effective, and the major difference is in side effects.[5] Medication selection should be based on clinical assessments of the individual patient - including clinical symptoms, preferences and tolerances for different side effects, previous response to the medication, and careful monitoring of the level of symptom control achieved on the currently prescribed antidepressant.[6] This can be best achieved when physicians and patients talk more fully and openly throughout the course of treatment and medication adjustments are tailored to each patient.

It is clear that addressing the communication gap is one necessary element in order to make further progress in improving quality of care for this disease and this patient population. Since there is no magic bullet, no one way to effect change in primary care physician practices to improve the management of depression, the best approach will require repetition of the message in various formats and through multiple channels.

Patients also must recognize that they, too, play a significant role in improving the therapeutic partnership, and look to their physicians for help to that end. Several survey findings can guide the primary care community towards areas to support physicians with patient education. Two examples include developing systems to enhance patient retention of treatment and side effect information and to encourage more patients to contact their doctor about any concerns, including side effects – instead of taking matters into their own hands by skipping doses or stopping medications.

Professional medical organizations need to recognize the importance and implications of the physician/patient partnership and include it as part of ongoing educational activities, such as at annual meetings, in continuing medical education courses, as part of medical school curricula, and as the topic of articles in publications.

In addition, primary care physicians and patients need better tools to help them communicate more effectively as a team about the treatment and recovery of the person with major depression, including the following ideas. Furthermore, to be most effective, these tools should be endorsed by and distributed through primary care organizations to increase the likelihood of their use by practicing physicians.

- **More effective communication tools are needed** to help the physician assess patient symptoms at baseline, monitor treatment, and distinguish symptoms of depression from treatment side effects – such as insomnia, sexual problems, weight gain, fatigue – as well as to guide physician decisions about which antidepressant class and medication best matches the patient's profile. Such tools, i.e., interview scripts, physician guides, patient journals/diaries, should also help physicians determine how well the antidepressant therapy is controlling patients' depression over time and serve as a measure for the need for changes or adjustments in the prescribed therapy.
- **Protocols should be developed for the primary care physician** to follow when discussing depression with patients that specify what questions to ask, how to phrase questions to elicit the most open and honest responses, and techniques for managing patient consultations, including working within time constraints.
- **Patient education materials written from the patient perspective** are equally necessary to reinforce physician messages communicated to individual patients about treatment and to foster more thorough and open follow-up discussions. Simple, sensitive and comprehensive materials should list potential side effects, with sections for patients to record questions, concerns and problems with treatment and side effects, and information to guide patients about when and who to call with their questions and concerns.

Conclusion

Increasingly, primary care physicians are the sole source of information and treatment for people with depression, including those who need long-term antidepressant therapy. Primary care physicians have accepted the responsibilities of diagnosing and treating depression, but neither they nor their patients have all the support and help required to manage this complex and persistent disease. Open, direct and ongoing communication between the patient and physician is a crucial step for evaluating the impact of treatment and the patient's recovery from depression.

The goal is better outcomes: patients and primary care doctors should strive for complete control of depression. Patients should not be left to believe that they have to tolerate problems with side effects needlessly. Side effects should not hinder compliance with therapy. Physicians should evaluate and consider the full selection of antidepressant classes and medications in order to tailor the prescription to patients' individual needs.

We urge influential medical and mental health organizations to take on this challenge and work to further improve the chances for recovery among those struggling with depression.

Survey Methodology

Beyond Diagnosis: A Landmark Survey on Depression and Treatment was conducted by Schulman, Ronca and Bucuvalas, Inc., a national research firm that specializes in health issues. The margin of error is ±3.1 percentage points at the 95% confidence level for the random sample of 1,001 patients and ±3.3 percentage points at the 95% confidence level for the random sample of 881 primary care physicians. For a copy of the full executive summary of the survey, contact National DMDA at (800) 826-3632.

Making Progress in Depression Awareness

Each year in the United States, depression affects more than 22 million adults[3] and results in 30,000 suicides.[7] Depression is a debilitating illness that robs people of sleep, peace of mind and concentration. It severely restricts one's ability to live, work and play. Results from the National DMDA survey, *Beyond Diagnosis: A Landmark Survey on Depression and Treatment*, reinforce the extent to which depression invades all aspects of life, including the toll it takes on personal and intimate relationships. Symptoms of depression include extreme sadness, anxiety, apathy and changes in sleeping and eating patterns. Risk factors for depression include prior episodes of depression, prior suicide attempts, a family history of depressive illness, lack of social support, stressful life events, and current substance or alcohol abuse.

In comparison to other medical conditions (hypertension, diabetes, advanced coronary artery disease, arthritis, back problems, lung problems and gastrointestinal disorders), people with depressive illnesses experience greater limitations in terms of physical and social function.[8] More than half of the patients in the National DMDA survey who were working said that depression has caused them to miss work. The mean number of days lost in the past 12 months was 22 for those employed full-time, 35 for those employed part-time.

Major depression is the number one cause of disability in the United States today. Depression is one of the most costly illnesses afflicting Americans, with annual costs estimated at $47 billion, compared to heart disease at $43 billion and chronic lung disease at $18 billion.[1, 9, 10]

In the last decade, awareness of depression as a treatable illness has increased along with the introduction of new classes of safer medications. These medications target the imbalance of brain chemicals (neurotransmitters) that cause depression and include selective serotonin reuptake inhibitors (such as Prozac, Paxil and Zoloft), selective serotonin/norepinephrine reuptake inhibitors (such as Effexor XR), and norepinephrine/dopamine reuptake inhibitors (such as Wellbutrin SR).

The role of patient advocacy groups, such as National DMDA, has significantly increased. These groups have worked to heighten public awareness to overcome the stigma of depression and encourage people to recognize the symptoms of depression and seek treatment. National Depression Screening Day was designated in 1991 as part of Mental Illness Awareness Week, which has been an annual event held during the first week of October since 1983. The White House hosted a Conference on Mental Illness in 1999 and the Surgeon General issued a report on mental illness in December 1999.

In addition, there have been a number of other recent programs designed to engage primary care physicians in the diagnosis and treatment of depression:

- In January 1997, the *Journal of the American Medical Association* published "The National Depressive and Manic-Depressive Association Consensus Statement on the Undertreatment of Depression."
- The MacArthur Foundation funded a Depression and Primary Care Initiative at Dartmouth Medical School, established in 1997.
- The American Academy of Family Physicians made mental health its clinical focus for 2000.
- The American College of Physicians-American Society of Internal Medicine issued antidepressant treatment guidelines in 2000.

National DMDA Meeting Participants

Primary Care Organizations

- American College of Physicians-American Society of Internal Medicine
- Association of Departments of Family Medicine
- American Medical Association
- American Medical Women's Association
- Illinois Academy of Family Physicians
- Society of General Internal Medicine
- Society of Teachers of Family Medicine
- The MacArthur Foundation Initiative on Depression & Primary Care at Dartmouth Medical School

Mental Health Organizations

- American Association for Marriage and Family Therapy
- American Psychiatric Association
- American Psychiatric Nurses Association

National DMDA Medical Advisors

- Thomas L. Schwenk, MD
  University of Michigan
  Professor and Chair, Department of Family Medicine
- Dwight L. Evans, MD
  University of Pennsylvania Health System
  Ruth Meltzer Professor and Chairman, Department of Psychiatry

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The National Depressive and Manic-Depressive Association

The National Depressive and Manic-Depressive Association (National DMDA) is the nation's largest patient-directed, illness-specific organization. Founded in 1986 and based in Chicago, we represent the voices of more than 20 million American adults living with depression and the additional 2.5 million adults living with manic depression, also known as bipolar disorder.

National DMDA is a nonprofit organization, committed to our mission of educating the public that mood disorders are treatable medical illnesses. Over 5,000 calls per month are personally answered on our toll-free information and referral line, (800) 826-3632, and our website, www.ndmda.org, receives more than 25,000 unique visits each month. We annually distribute more than 50,000 information packets free of charge to anyone requesting information about mood disorders.

National DMDA has a prestigious 65-member Scientific Advisory Board composed of the leading researchers and clinicians in the field of mood disorders who join patients, family members and members of the mental health advocacy community at our annual conference to share the most current research and treatment information.

National DMDA has a grassroots network of more than 400 support groups that holds regular meetings across the United States and Canada. Nearly 100,000 people attend DMDA meetings every year. Support groups play an important role in recovery with *nearly 94% of support group members reporting that their group helped with treatment compliance.* This is a key finding with regard to cutting medical costs because treatment compliance means decreased hospital stays, which in turn means lower insurance costs.

National DMDA publishes a variety of educational materials for adults and teens on the treatment of mood disorders, all available free of charge or for a nominal fee. Because we focus on the consumer living with a mood disorder, our publications are written in language free from medical and scientific jargon, and everything we produce conveys a strong message of hope and optimism.

National DMDA maintains a bookstore with more than 70 titles of print and audiovisual materials focusing on mood disorders and related topics.

National DMDA annually convenes a national conference for its constituents and it also produces high level scientific conferences. In addition, we sponsor consumer surveys on issues of importance to those living with mood disorders.

The National DMDA initiative, *Beyond Diagnosis: Depression and Treatment,* was sponsored by an unrestricted educational grant from Glaxo Wellcome, Inc.

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