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**First-ever International Caregiver Survey to Show Treatment Disruption  
Has Serious Consequences for Families Living with Serious Mental Illness**  
*Caregivers Ask Doctors to Focus on Maintaining Long-Term Wellness*

**PARIS - September 18, 2006** - The disruption of a family member's treatment for mental illness and subsequent worsening of psychiatric symptoms can have harsh financial, physical and emotional consequences for families. *Keeping Care Complete*, an international survey of 982 family caregivers of individuals with schizophrenia, bipolar disorder and schizoaffective disorder, reveals the devastating consequences of relapse - defined as the worsening of symptoms after apparent recovery - and sheds light on a desire among caregivers for doctors to focus on long-term care rather than managing crisis situations.

"More than 50 million people suffer from serious mental illnesses worldwide. When you consider all of the parents, siblings, spouses and children connected to these individuals, you see how far the shadow of serious mental illness is cast," said Preston J. Garrison, Secretary-General and Chief Executive Officer, World Federation for Mental Health (WFMH). "This survey shows that many caregivers have experienced both the chaos of relapse and the relief that comes with stabilization."

*Keeping Care Complete* was developed by the WFMH and Eli Lilly and Company. Independent market research company Ipsos conducted the survey of caregivers in Australia, Canada, Germany, France, Italy, Spain, the United Kingdom and the United States.

**Relapse Consequences and Triggers**

Caregivers whose family members experienced relapse reported that as a result, their loved ones were unable to work, were hospitalized, tried to commit suicide and/or were incarcerated. Many of these caregivers also said that their own mental and physical health and financial situation deteriorated following the relapse. Among the 502 caregivers whose family members stopped taking their medication, 91 percent reported their family member relapsed after discontinuation. In addition, 56 percent of the 455 caregivers who said their family member's medication was changed based on a decision made in cooperation with the doctor their loved one experienced relapse after the switch.

“Once patients find a medication that works for them, it is important for them to stay on it. Attempts to save resources by limiting access to newer medications can fail when a switch to a different treatment, which may lead to treatment discontinuation and later trigger a relapse, ultimately increases costs for hospitalization and other rehabilitative services,” said Prof. Dr. Dieter Naber, Director of Department of Psychiatry and Psychotherapy at the University Medical Center Hamburg-Eppendorf in Germany, who served as a medical advisor for the survey. “Before a switch is made, doctors have to weigh risks and benefits of each treatment option while taking into consideration an individual’s potential reaction to a new medication.”

### **Efficacy is top treatment priority for caregivers**

Nine in ten caregivers surveyed agreed that efficacy is their primary concern when weighing treatment options for their family member and that an effective medication is needed to control symptoms, before overall well-being and health can be properly tackled. Results further showed that caregivers who say their relative is satisfied with their current medication believe that effective treatment has enabled their family members to perform daily tasks more independently, stay out of the hospital and hold a steady job or volunteer position. In addition to medication, caregivers cited family support and social support, talk therapy, exercise, having responsibilities and a stable schedule among key factors that help keep their family member well.

### **Desire to raise expectations and focus on long-term wellness**

Most caregivers say physicians should focus on long-term management of their loved one’s mental illness rather than managing crisis situations: 66 percent of caregivers said that they are frustrated by a doctor’s approach to set very low goals for long-term improvement of the relative’s illness.

*"Keeping Care Complete* highlights the complete circle of care that is ideal for achieving long-term wellness for people, like my son, who are living with a serious mental illness. The complete circle of care includes a safe and stable relationship with a treatment team, effective medication suited to an individual's needs, well-funded community-based wellness and other social support programs, and informed family caregivers that have the support they need to remain strong and to encourage their loved ones," says Sigrid Steffen, family member and vice president of EUFAMI, the European Federation of Associations of Families of People with Mental Illness. "As shown in the survey, family members can provide significant insight into these devastating but treatable illnesses."

International survey data and fact sheets on schizophrenia, schizoaffective and bipolar disorder and the caregiver perspective are available at [www.wfmh.com](http://www.wfmh.com).

## **About Bipolar Disorder, Schizophrenia and Schizoaffective Disorder**

Bipolar disorder, schizophrenia and schizoaffective disorder are complex mental illnesses that know no racial, cultural or economic boundaries.<sup>1</sup> Bipolar disorder, formerly known as manic-depression, is characterized by debilitating mood swings with symptoms categorized by mania and depression.<sup>2</sup> Schizophrenia is characterized by acute psychotic episodes including delusions (false beliefs that cannot be corrected by reason), hallucinations (usually in the form of non-existent voices or visions) and long-term impairments such as diminished emotion, lack of interest and depressive symptoms, such as hopelessness and suicidal thoughts.<sup>3</sup> Schizoaffective disorder is characterized by a combination of symptoms of schizophrenia and an affective (mood) disorder. Twenty-seven million people suffer from bipolar disorder and 24 million people suffer from schizophrenia worldwide.<sup>4,5</sup> Although the exact prevalence of schizoaffective disorder is not clear, it is estimated to range from two to five in a thousand people. Schizoaffective disorder may also account for one-fourth or even one-third of all persons with schizophrenia.<sup>6</sup>

## **About WFMH**

WFMH is an international interdisciplinary membership organization whose mission is to promote, among all people and nations, the highest possible level of mental health in its broadest biological, medical, educational, and social aspect. Consultative status at the United Nations provides WFMH a variety of opportunities to engage in mental health advocacy at the global level, working closely with the World Health Organization, UNESCO, the UN High Commissioner for Refugees, the UN Commission on Human Rights, the International Labor Organization and others. Additional information about WFMH is available at [www.wfmh.org](http://www.wfmh.org).

## **About Eli Lilly and Company**

Lilly, a leading innovation-driven corporation, is developing a growing portfolio of first-in-class and best-in-class pharmaceutical products by applying the latest research from its own worldwide laboratories and from collaborations with eminent scientific organizations. Headquartered in Indianapolis, Ind., Lilly provides answers – through medicines and information – for some of the world's most urgent medical needs. Additional information about Lilly is available at [www.lilly.com](http://www.lilly.com).



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<sup>1</sup> Schizophrenia: What You Need to Know. National Mental Health Association. Available at: <http://www.nmha.org/infoctr/factsheets/51.cfm>, accessed June 7, 2006.

<sup>2</sup> Bipolar Disorder. National Institute of Mental Health. Reprinted September 2002. Available at: <http://www.nimh.nih.gov/publicat/bipolar.cfm>, accessed June 7, 2006.

<sup>3</sup> Weiden P, Scheifler P, Diamond R, et al. *Breakthroughs in Antipsychotic Medications*. New York: W.W. Norton & Company, 1999.

<sup>4</sup> The World Health Report 2001: Mental Health – New Understanding, New Hope. World Health Organization. Available at: <http://www.who.int/whr/2001/chapter3/en/index1.html>, accessed January 6, 2006.

<sup>5</sup> The Global Burden of Disease. World Health Organization in 2003. Available at: [http://www.who.int/mip/2003/other\\_documents/en/globalburdenofdisease.pdf](http://www.who.int/mip/2003/other_documents/en/globalburdenofdisease.pdf), accessed January 6, 2006.

<sup>6</sup> Schizoaffective Disorder. National Alliance on Mental Illness. Available at [http://www.nami.org/Template.cfm?Section=By\\_Illness&template=/ContentManagement/ContentDisplay.cfm&ContentID=11837](http://www.nami.org/Template.cfm?Section=By_Illness&template=/ContentManagement/ContentDisplay.cfm&ContentID=11837), accessed June 7, 2006.