



# THE BELL

The newsletter of the National Mental Health Association ■ August 2001

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## NMHA State Advocacy Update

See center insert for updates on key issues that affect state advocates, consumers and the mental health community-at-large, including:

- State Advocacy Efforts
- Federal Legislation
- Healthcare Reform Advocacy Trainings
- NMHA's Advocacy Resource Center

## Senate Committee Passes Full Parity

Millions of Americans with mental illness are a step closer to getting coverage for needed mental health treatment thanks to the recent passage of the Mental Health Equitable Treatment Act of 2001 by the U.S. Senate Committee on Health, Education, Labor and Pension (HELP).

NMHA President and CEO Michael M. Faenza praised the HELP Committee for its action on the bill. "It will go a long way toward finally ending the appalling practice of healthcare discrimination that denies people access to necessary therapies," Faenza said of the legislation.

The bill, cosponsored by Sens. Pete Domenici, R-N.M., and Paul Wellstone, D-Minn., is expected to go to the full Senate soon after Congress returns from its summer recess Sept. 3. The committee's unanimous vote paves the way for the Senate to move on the legislation before the 1996 Mental Health Parity Act expires Oct. 1. If passed, the bill will go to the House of Representatives for a final vote.

The act, Senate Bill 543, would require group health plans that offer mental health benefits to provide mental health coverage that is on par with medical and surgical benefits. It would also narrow exemptions available in the current 1996 federal parity law that allow employers to limit hospital stays and outpatient visits, and impose high copayments and deductibles. The measure calls for parity for all mental disorders but does not cover substance abuse.

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## MHA Takes on Status Quo For Latino Community



The Mental Health Association of Middle Tennessee started the "Encuentro Latino" program to help connect Nashville's rapidly growing Latino population to the area's mental health services. Pictured above are teenagers who participate in one of the MHA's focus groups organized to help assess their peers' needs. See page 4 for the full story.

## From the President

In the last few months, NMHA has released two surveys that tell a story of hope and progress but also speak to the many obstacles we still face in overcoming stigma and discrimination.

Our "Disease or State of Mind?" survey featured in this issue shows exciting improvements in attitudes about depression from 10 years ago, yet also exposes several hurdles people encounter when seeking care for their illness. Our "America's Mental Health Survey" covered in last month's Bell reveals the impact shame and misconceptions have in keeping people from seeking treatment and getting better.

The remaining gaps in understanding and disparities in access help to explain why we are still fighting battles for parity in health care coverage in states and on Capitol Hill. Although we have come far, we still have a long way to go in changing minds about mental health.

At NMHA, we understand that it's often necessary to educate as we advocate. Whether it's the classroom, boardroom or legislature, we make sure our positive messages about mental health are heard. Through the combined power of public education and advocacy, we can counter the misunderstandings that keep people from living fuller lives.

Sincerely,



Michael M. Faenza  
President and CEO



## What's on the Horizon for Refractory Depression Therapy?

by Susan Weiss, Ph.D., senior director, Research, NMHA

Although depression is a common and treatable form of mental illness, some people suffer from a form of severe and chronic depression that fails to respond to conventional treatment and medication. These people have "refractory depression," which is estimated to affect between 10 and 15 percent of people with unipolar or bipolar depression.

One promising technique now offers hope to those with refractory depression. It involves the use of an implanted device called a vagus nerve stimulator (VNS), which is already used to treat severe epilepsy and now shows promise for depression treatment. The device, which is about the size of a pocket watch, is implanted under the skin in the upper chest region, and functions similarly to a cardiac pacemaker. It sends electrical signals to the vagus nerve, which communicates to the brain's wide-reaching neural networks.

VNS development began in 1985 when animal research demonstrated that vagus nerve stimulation could inhibit seizures. Since the Food and Drug Administration's 1997 approval of VNS for refractory epilepsy, more than 9,000 people worldwide have been fitted with the device.

Psychiatrists first noticed VNS as a potential depression therapy when some people using the device for epilepsy reported a substantial improvement in their moods—whether or not their seizures were reduced. The reasons why treatment for epilepsy and mood disorders overlap are unclear, but the brain areas involved in emotion and memory are also the most vulnerable to disruption by epilepsy. In fact, many mood stabilizers used for bipolar illness are also anticonvulsants that were originally developed to treat epilepsy.

A recent clinical trial involving 30 patients with refractory depression shows that 40 percent showed marked improvement with VNS treatment. Among the most encouraging study results are the device's persistent antidepressant effect over time and, in many cases, an increased therapeutic benefit with long-term use (note that study participants took medication along with the VNS treatment).

VNS has surprisingly few side effects—the most commonly reported problem is hoarseness. Some people with epilepsy have experienced side effects that required the device's removal, but no long-term effects have been reported. In addition, VNS patients can use a magnetic device to shut off the stimulator at any time by placing it over the VNS implant in their chest area, or the stimulator can be removed permanently, if necessary.

Using VNS as a treatment for depression remains experimental but is being tested in a clinical trial designed to meet FDA standards for approval. Canada has already approved VNS for use in depression.

Vagal nerve stimulation may be the first of a variety of approaches used to treat people with severe mental illnesses who do not respond to available therapies. And for people with treatment-refractory depression, these new possibilities bring hope for a better life. 

# Disease or State of Mind?

## NMHA Survey Reveals Public's Growing Understanding of Depression

NMHA's latest national survey shows dramatic improvement in the public's understanding of clinical depression. Despite this promising trend, the survey also shed light on the difficulties millions of people face when striving to manage this sometimes chronic, life-long illness.

The survey found a major shift in the last decade in public perception of the origins of clinical depression. Although only 38 percent of people surveyed in 1991 agreed that depression is an illness and not a "state of mind that a person can snap out of," this year a majority (55 percent) of respondents agree that depression is an illness.

"This increased understanding represents real progress," said Michael Faenza, NMHA president and CEO. "Perhaps for the first time in history, more people than not understand that depression is a treatable illness—not a choice."

Along with this promising news, the survey identified the need for progress on several fronts, especially in educating the 31 percent of respondents who do not acknowledge that depression is a real illness. "You'd never hear that many people deny that diabetes and heart disease are real," said Faenza.

In addition, even though survey respondents with depression overwhelmingly feel that treatment works, they also report difficulties in maintaining a treatment plan. Nearly one-third of respondents who use antidepressants report skipping doses, and about one-fourth of respondents in psychotherapy report missing sessions.

The survey isolated several factors that work against strict adherence to treatment plans, including many managed care organizations' unwillingness to cover an appropriate course of psychotherapy despite strong evidence that a combination of psychotherapy and medication is the best treatment for severe depression.

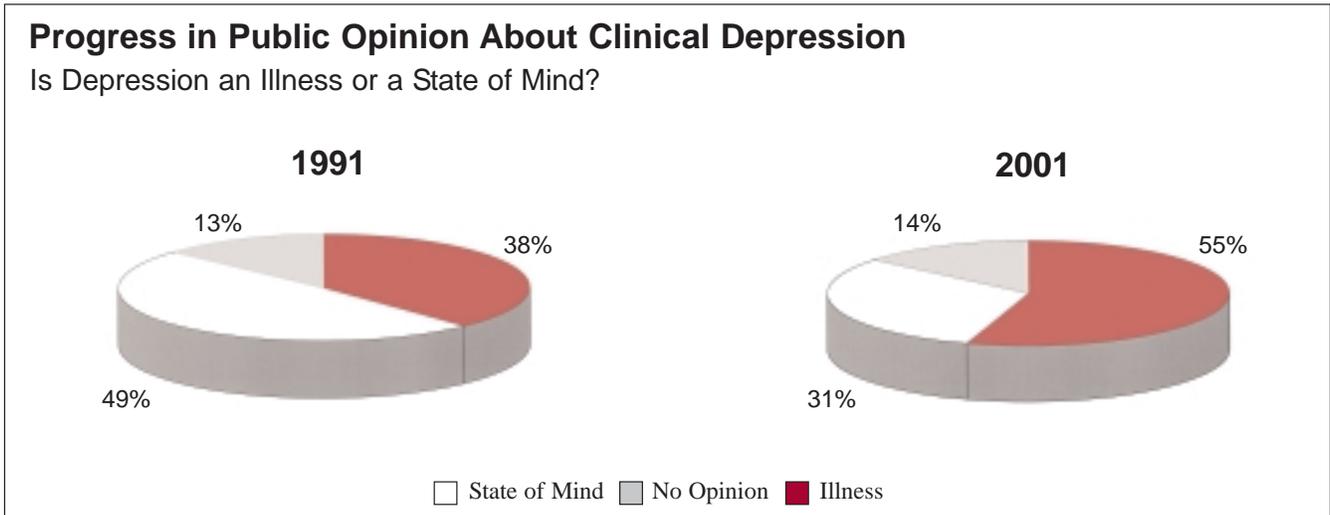
Many of those surveyed who have clinical depression are less well off socially and economically than people without depression. Survey respondents with depression are more likely to be divorced and unemployed. They also are more likely to have lower incomes and less formal education.

"Although we've come a long way in the last decade," said Faenza, "erroneous beliefs about depression fuel stigma, bad public policies and poor personal choices by those living with the illness that may impede their recovery."

The NMHA survey, was conducted by Public Opinion Strategies LLC and made possible through an unrestricted educational grant from Eli Lilly and Company. Look for the full report on NMHA's Web site at <http://www.nmha.org>.

The findings from this survey are based on telephone interviews with three groups: 500 adults ages 21-70 currently being treated for depression; 300 healthcare providers who treat people with depression (100 each of primary care physicians, psychiatrists and psychologists); and 800 adults over age 18.

The margin of error for each sample segment: people with depression = ±4.38 percent; healthcare providers = ±5.66 percent; general public = ±3.46 percent.



### At a Glance:

#### MHA of Middle Tennessee

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#### Other Programs

- **J. Speed Thomas Mental Health Assistance Center** helps clients identify problems and provides consultation, support and information about mental illness and community resources with outreach to Latino community.
- **Aging Services Program** provides free support groups, consultations, respite and educational programs for caregivers of loved ones with Alzheimer's or dementia.
- **Erasing the Stigma** is a statewide education program that includes Kids on the Block presentations, I.C. Hope curriculum for schools and the Campaign for America's Mental Health.
- **TennCare Partners Advocacy Line (TPAL)** provides enrollment assistance, benefits information and advocacy to the 1.5 million people eligible for mental health and substance abuse services under the TennCare Partners program.

## MHA of Middle Tennessee Takes On Status Quo for Latino Community

by Fran Peebles, clinical director, MHA in Middle Tennessee

It started with a phone call four years ago. The caller asked for a Spanish-speaking therapist for her husband, who was depressed and spoke no English. I had worked in this community for many years but knew of no Spanish-speaking psychiatrist, social worker or psychologist in Nashville. I apologized to the caller for not being able to help.

As new Latino immigrants began arriving daily from Mexico and war-torn countries in Central and South America, the need for Spanish-speaking mental health counselors in our community increased. These immigrants, mostly undocumented, experience family separations, family upheavals caused by cultural changes, fear, anxiety, depression, substance abuse and domestic violence. I began attending Latino events and meetings, hoping to find Spanish-speaking mental health professionals to help these people. I still found none.

In response, we formed a coalition with five other local community and health organizations, and approached the Frist Foundation for help meeting the social service needs of Nashville's Latino population. This local foundation offered to provide funding for a community survey to document the assets and needs of the Latino community. We put out a call to other nonprofit agencies that wanted to provide services to Latinos and asked them to join us for a meeting in the spring of 2000. That's when Encuentro Latino, or Latin Encounter, began.

After completing a survey that included 15 Spanish-speaking focus groups, Encuentro Latino presented the assets/needs study findings to the Nashville community last fall at a public meeting with professionals from all levels of government, private and nonprofit organizations. The meeting addressed major issues such as health (including mental health), education, immigration, transportation, housing, social services, business and civil rights (see the full report at [www.UWMN.org](http://www.UWMN.org)).

As a result of our study and collaboration, we have increased public awareness of the needs of the Latino population and initiated collaborative grant-writing efforts among agencies. We also helped form a Hispanic Advisory Committee to the Metropolitan Health Department. On the legislative front, we successfully advocated for the passage of a statewide driver's license bill that will allow immigrants to get a license without a social security number. And the governor has invited members of the Latino community to discuss their issues with him.

Our biggest lesson was learning the true value of collaboration, which strengthens requests for funds and gives us a louder voice in the process. Banding together also allows us to provide services that we otherwise couldn't offer. For example, five non-profit agencies have joined together to offer free Spanish-speaking support groups for husbands, wives and children living with domestic violence. We also established a monthly meeting during which we examine the mental health needs of and services for the Latino community. In addition, we learned to be open to help from secondary resources and employ several unpaid interns from local universities to help with our hotline and other work.

We have also learned to reach out to Latino mental health professional newcomers, and agencies with needs similar to ours and invite them to join us. With patience, as we hold firm together, the group, like a magnet, draws in those that can help meet the mental health needs of the Latino community. And now, when I receive requests for referrals to Spanish-speaking mental health professionals, I am happy to be able to help. 📌

# State Advocacy Update

## MHA State Advocacy Efforts Move Beyond Budget Issues

States have seen the legislative landscape shift this year as budget surpluses turned to deficits. Many mental health advocates are now playing defensive roles, protecting scarce mental health resources and access to treatment and services. This is a striking contrast to state legislative activity in previous years, which often focused on leveraging state budget surpluses for unmet mental health needs.

But state policy activity this year has not been entirely budget-focused. Across the country, Mental Health Associations are addressing key issues such as access to psychotropic medications, mental health and substance abuse parity, involuntary outpatient commitment and *Olmstead* planning.

NMHA is now holding focus groups with state advocates to determine the resources they need to protect and expand access to community-based services and treatment. This fall, NMHA will provide advocates with targeted assistance and materials based on the focus group outcomes. Technical assistance is currently available to advocates on budget issues, including cost-offset information, Medicaid data and state

options, formulary restrictions, guidance on the state appropriations process, and strategic consultation on specific state issues.

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### Access to Psychotropic Medications

Budgetary concerns have led several states to reduce access to needed medications through formulary

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## Federal Update: Patients' Rights Legislation Alone Is Not a Panacea

*Consumers Need Mental Health Parity*

Recent congressional debates on patients' rights legislation underscore the importance of health insurance and health security to Americans. Yet for people with mental illness, having health insurance — even with the protections that the Senate-passed patients' rights bill would provide — does not necessarily ensure access to needed treatment or protection against financial catastrophe. The reason? Most health insurance policies provide much more limited benefits for mental health care than for treatment of other health problems.

As mental health advocates know all too well, health insurance policies routinely limit the duration of mental health treatment, and often impose strict limits unrelated to medical need. Many health insurance policies also impose extraordinary cost-sharing requirements that are not required for medical or surgical problems, which means many people lack the resources to get any treatment. These arbitrary limitations and additional financial burdens are unfair.

The adoption of patients' rights legislation, important as it is, will not remedy most health insurance practices that discriminate against people with mental illness, and will leave millions of families vulnerable. The Senate-

*Continued on page 3-a*

## Healthcare Reform Advocacy Trainings Continue Spring/Summer Update

NMHA continues to offer advocacy trainings in conjunction with state and local affiliates geared to the specific needs and priorities of state mental health coalitions. Successful trainings conducted this spring and summer include:

**Maryland** — The MHA of Maryland brought together state advocates in May to strategically respond to Involuntary Outpatient Commitment (IOC) legislative initiatives slated for the 2002 legislative session. Historically, advocates in Maryland have easily defeated IOC legislation; however, recent support for IOC has forced advocates to be more proactive.

**Arizona** — The MHA of Arizona met with a host of state advocates in May to address systems of care for children, with a particular focus on access to medication for children and adolescents as a component of care. Participants developed an action plan to highlight disparities in children's mental health care and outlined specific efforts to enhance resources in the state. This plan is projected over a 12-month time line.

**Delaware** — In an effort to call attention to the needs of consumers of mental health and substance abuse services, the MHA of Delaware met in May with a wide range of local coalition members to develop strategies for better coordinating systems that serve individuals with co-occurring disorders. Participants also met with state officials to discuss mental health and substance abuse program development within the justice system.

**Georgia** — The NMHA of Georgia hosted a meeting of mental health coalition members to analyze the state's existing mental health agency. Participants identified the

most effective measures to enhance the resources and delivery of mental health services throughout the state.

**Vermont** — Stakeholders met with the MHA of Vermont to look at ways in which the state can better coordinate a system of services for children, adolescents and young adults. Training participants analyzed the state's existing systems of care for children and adolescents, and developed strategies for expanding the scope of mental health services to include youth between the ages of 18 and 22. In particular, participants examined the needs of youth in transition to adult mental health systems.

If you anticipate problems regarding legislation or regulatory policy, or if you need to create or expand a mental health coalition, please feel free to contact us for assistance. We are ready to help.

For more information, contact Dave Nelson at 703-797-2594 or [dnelson@nmha.org](mailto:dnelson@nmha.org), or Terri Odom at 703-838-7554 or [todom@nmha.org](mailto:todom@nmha.org). **SAU**

### Correction:

*An update in the previous issue of SAU on the MHA in Louisiana's activities was incorrect. The correct report follows:*

During a February Healthcare Reform Training, the MHA of Louisiana worked with state advocates on a Medicaid Buy-In initiative. Legislation to adopt a Medicaid Buy-In program was not introduced, but the legislature passed a resolution to conduct a feasibility study to identify the infrastructure needs for the current service system and apply for federal funding to enhance the infrastructure of the Department of Health and Hospitals.

## Lobbying Guide Offers Tips and Tools For Promoting Change

NMHA has released a new advocacy primer designed to help advocates effect mental health policy changes. The new booklet, *Influencing Your State Legislature*, outlines the basics of how to lobby members of state legislatures to transform behavioral health policy goals into state law and to prevent harmful legislation from becoming law. The primer includes four case studies detailing successful advocacy efforts by Mental Health Associations, and provides samples of legislative alerts, testimony and letters to the editor. *Influencing Your State Legislature* is available for \$5.00 by calling 800-969-NMHA (6642). **SAU**



## Federal Update: Patient's Rights Alone Is Not a Panacea

*Continued from SAU front page*

passed Bipartisan Patient Protection Act would require health insurers to live up to their contract obligations and protect consumers' rights, but it won't make discriminatory coverage of mental illness illegal. In addition, the weaker House-passed patient rights bill also permits discriminatory mental healthcare coverage. Stamping out discriminatory barriers to mental health insurance coverage will require Congress to enact specific legislation requiring parity between mental health coverage and coverage for medical and surgical care. The Mental Health Equitable Treatment Act of 2001, S. 543, would provide that remedy.

The fight for mental health parity is important not only for people with health insurance. It has precedent-setting value for future battles on a broad range of issues. Parity is fundamentally a civil rights issue, so achieving this goal is a key to further progress on other social justice issues.

S. 543, introduced by Sens. Pete Domenici, R-N.M., and Paul Wellstone, D-Minn., would for the first time prohibit a group health plan from imposing treatment limitations or financial requirements on mental health coverage unless comparable limits are imposed on medical and surgical benefits. The bill would also close gaps in the Mental Health Parity Act of 1996, which was a first step toward achieving mental health parity. The expiration of the 1996 parity law on September 30 makes it critical that a strong parity bill win congressional approval in the coming month.

On July 11, the Senate Health, Education, Labor and Pensions (HELP) Committee, under chairman Sen. Ted Kennedy, D-Mass., held a long-anticipated hearing on mental health parity to support favorable action on mental health parity legislation. Domenici testified that the Congressional Budget Office (CBO) has determined that enactment of S. 543 would result in only a 1 percent increase in insurance premiums, proving that mental health parity is affordable.

This analysis

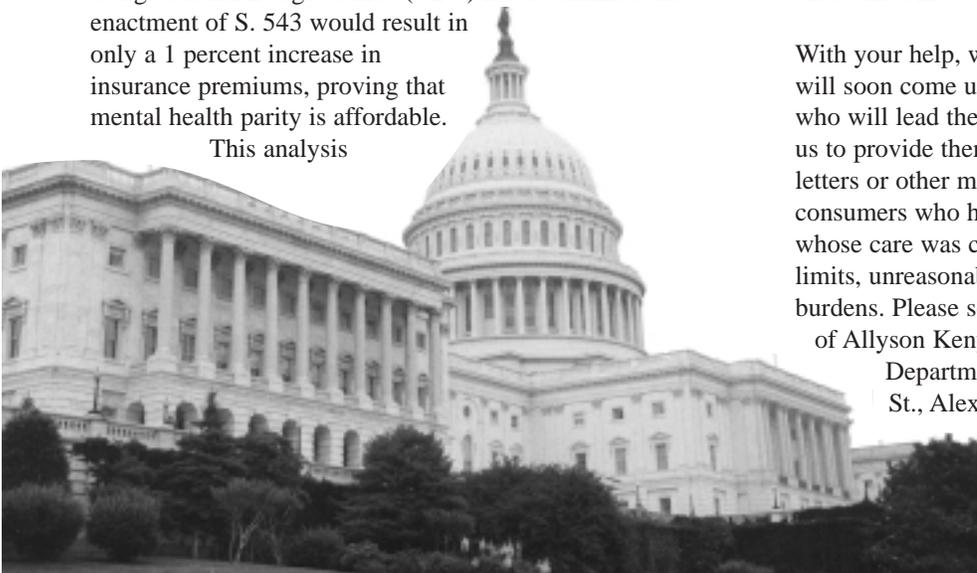
and assessment by the CBO should aptly address concerns regarding the cost-impact of enacting mental health parity. The Committee also heard testimony from the Office of Personnel Management (OPM) regarding its early experience with mental health and substance abuse parity under the Federal Employee Health Benefit Program. OPM's testimony supported the CBO's conclusion that parity could be successfully implemented with only limited additional cost.

Perhaps consumer Lisa Cohen provided the most compelling testimony. Her story was brought to NMHA's attention by the MHA of Southeastern Pennsylvania. Lisa compared the benefits and treatments she currently receives through her insurance provider for two life-threatening conditions: a blood disorder and bipolar disorder. In her experience, the insurance company had no problem covering the majority of the costs to treat her blood disorder, yet severely limited her mental health benefits, forcing Lisa, with the help of family, to pay for her treatment out-of-pocket.

Fifty-four senators representing both parties and the Senate's lone independent signaled their support for parity by cosponsoring S. 543. Although the Senate HELP Committee unanimously approved an amended version of the bill recently, advocates have more work to do. Grassroots efforts are vital to our success. We need to persuade uncommitted Senators to cosponsor this bill. We must also win more support among members of the House of Representatives for a similar House bill, H.R. 162. To do so, we must put a human face on the issue of mental health parity, which can help focus the debate on the tragic consequences of denying parity and the compelling need to enact this bill.

With your help, we can do that. We anticipate that this bill will soon come up for floor debate in the Senate. Senators who will lead the fight for parity in this debate have urged us to provide them with personal stories. Please send us letters or other materials that provide personal accounts of consumers who have private health insurance coverage but whose care was cut short because of arbitrary treatment limits, unreasonable costs or discriminatory cost-sharing burdens. Please send those personal stories to the attention of Allyson Kenyon, NMHA Government Affairs

Department at [akenyon@nmha.org](mailto:akenyon@nmha.org) or 1021 Prince St., Alexandria, VA 22314. Or fax your stories to 202-675-8389. **SAU**



# Technical Assistance Resource Center Grows to Support Diverse Audience

Given its recent growth and increased capacity to handle requests, NMHA's Advocacy Resource Center is quickly becoming the leading source for healthcare reform information and assistance in the mental health field. The Center now serves a wide network of advocates who seek NMHA assistance for public policy information, resources, research and consultation.

Developed in 1998 to enhance the efforts of the Healthcare Reform Advocacy Training and Technical Assistance Program supporting local advocates, the Center's audience now also includes family members, consumers, state legislators, providers, mental health professionals, the media, managed care organizations, and local and national agencies.

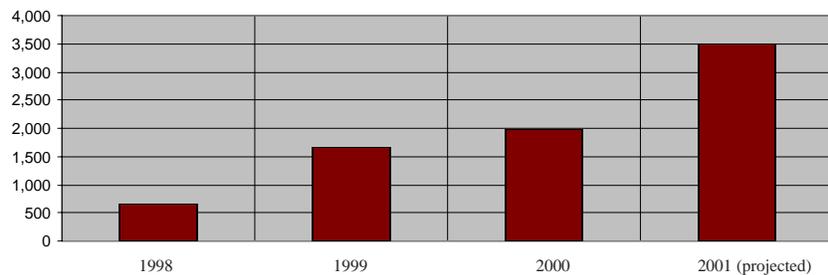
Last year, the Advocacy Resource Center responded to 1,947 requests for technical assistance. The Center has fulfilled more than 4,000 requests since its inception.

## Scope of Technical Assistance

The Center fills technical assistance requests on a broad variety of topics. On any given day, the Center's callers may request information on state-specific information

related to health insurance parity, statistics on per capita spending on mental health or the adverse effects of restrictive drug formularies. Although some requests take only a short time to fulfill, others require extensive research that can take days to complete.

**Number of Requests for Health Policy Information and Assistance**



Of the 1,947 requests for research, consultation and resources the Center fulfilled last year, a vast majority — 1,739 — are from outside NMHA. The Center also distributed publications to more than 4,000 individuals and groups last year.

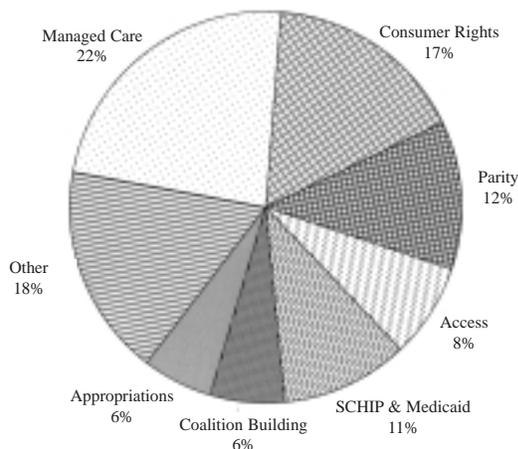
External requests in 2000 for technical assistance came from a variety of sources (external requests are those received from MHAs, consumers, clinicians, state officials, or other organizations or individuals not employed by NMHA). Most of these requests originated from advocates interested in strengthening their advocacy efforts. Other groups contacting the Center included state and national government agencies in search of information on specific mental health and policy issues.

The Center is expected to respond to more than 3,500 requests in 2001 alone.

## Pre-Training Research and Ongoing Technical Assistance

The Center provides ongoing technical assistance to advocates that participate in the Healthcare Reform Advocacy Training Program. This program conducts more than 20 trainings per year in states across the

**Types of Health Policy Information and Assistance Requests in 2000**



country. Assistance includes both pretraining research and follow-up technical assistance. Pretraining research consists of compiling information on the state's mental health system and challenges and providing information specific to the topics covered during the training. The follow-up assistance provides advocates with many tools to achieve the goals outlined in the action plans created at the trainings.

For more information about NMHA's Advocacy Resource Center, call 800-969-NMHA (6642) and choose option 6. **SAU**

## New Online Resource for Substance Abuse/Addiction Information

NMHA has expanded its Web site (<http://www.nmha.org>) to include a new substance abuse prevention and treatment section that includes research-based data, Internet links to substance abuse information, and a new NMHA publication on substance abuse treatment disparities for women of color.

The publication, "Meeting the Challenge: Ending Treatment Disparities for Women of Color," is a call to action for all community leaders, substance abuse/addiction stakeholders and treatment providers. It

offers information to help them work across systems, races and cultures to develop pathways for women of color to access services that reflect—and respond to—their needs and experiences.

NMHA developed the document as part of the Targeted Technical

Assistance Project of the National Association of State Mental Health Program Directors and the Division of State and Community Systems Development of the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.



## Some Medicaid Facts

When planning state advocacy strategies, make sure to build and maintain relationships with your state Medicaid office. Medicaid has become a major payer for public mental health services.

### Did You Know . . . ?

- Services provided under Medicaid account for more than half of all public mental health services provided at the state and local levels.
- There are no state or federal requirements for Medicaid agencies to produce statistics on mental health services and spending.
- According to a February 2001 Medicaid letter, states must respond within 24 hours to prescription requests for the new atypical antipsychotic medications.
- Medicaid requires that states develop a yearly mental health plan if they provide mental health services, but this requirement is not enforced.

### What Is a Home- and Community-Based Waiver?

As states work to implement the *Olmstead* decision, they may seek to use Medicaid to fund integrated home- and community-based services. States can apply for Medicaid waivers to fund such alternative services. States should note, though, that federal law prohibits funding for services in Institutions for Mental Diseases (IMDs) for people between the ages of 22 and 64. (IMDs are residential facilities with more than 16 beds that primarily serve people with mental health or substance abuse disorders.) States *can*, however, apply for the Home- and Community-Based Waiver for:

- Children under age 21
- Adults over age 64 in certain states
- Any adults who live in nursing homes that are not primarily IMDs

For more information about planning state advocacy strategies related to Medicaid, call the NMHA Advocacy Resource Center at 800-969-NMHA (6642) and select option 6.

## MHA State Advocacy Efforts Move Beyond Budget Issues

*Continued from SAU front page*

restrictions. By restricting access, states hope to lower costs in their Medicaid pharmaceutical line items. Research clearly indicates, however, that such efforts not only jeopardize consumer health but also fail to reduce costs because expenses for hospitalization, community mental health services, and emergency care increase when prescribers and consumers are unable to choose appropriate treatments.

This year has seen much legislative activity on formularies. In **Florida**, the legislature enacted a new closed formulary that limits access to needed medications and places limits on the number of medications that can be received by individuals in the Medicaid program. For years, a broad-based coalition of advocates from MHAs and many disability groups in this state opposed these restrictions. Through their efforts, medications for mental health and HIV/AIDS were exempted from new restrictions. Similar exemptions were also made to new formulary restrictions being considered in Oregon this year.

In response to proposed Medicaid restrictions in **Indiana**, the MHA of Indiana successfully pushed for legislation that prohibited Medicaid from enacting restrictions on access to medications. Although the bill passed in the legislature, Governor Frank O'Bannon vetoed it. The governor, however, has subsequently contacted advocates to develop compromise legislation, acknowledging that stakeholders will continue to seek legislative protections against formulary restrictions in the Medicaid program.

Restrictions on access to medications have been enacted this year in **Louisiana** and are being considered in legislatures and Medicaid offices across the country. To address these trends in **New York**, advocates there earlier this year invited NMHA to conduct a training on the benefits of open access to assist their lobbying efforts in the state legislature. The MHA of New York is building on this event by developing similar regional trainings across the state.

To support advocacy in this area, NMHA has developed multiple resources, including *Pennywise Pound Foolish: Restricting Access to Psychotropic Medications*, an advocacy guide available for a minimal cost. NMHA is also developing a new document that outlines legislative language that has been proposed or enacted in states to maintain open access to medications or mediate restrictive bills when they are enacted. To order these materials, call 800-969-NMHA (6642) and select option 6.

### Mental Health and Substance Abuse Parity

NMHA is advocating for federal and state governments to enact parity protections requiring all health plans to ensure that coverage for mental health and substance abuse care is on par with medical and surgical benefits. Thirty-four states have enacted laws to prevent insurance companies from discriminating against mental health in benefit plans. In 2001, 70 bills related to coverage for mental health and/or substance abuse have been introduced in 24 states. Many states that currently have parity laws are revisiting them to expand mental health coverage or to add provisions related to substance abuse.

In **Arkansas**, a law was enacted this year to provide parity benefits under the state's children's health insurance program. **Indiana** and **Arizona** also secured parity this year for substance abuse disorders within both states' employee health plans. In **Colorado**, a law has been enacted amending the state's parity law to require that insurance carriers use a preauthorization or utilization review mechanism that is no more restrictive than that used for physical illness. **Delaware** has expanded its current parity law to include substance abuse treatment. **Rhode Island** has also expanded its parity law to cover all mental disorders under the current version of the *Diagnostics and Statistical Manual of Mental Disorders*, including substance abuse disorders.

**Illinois** has passed a limited parity law, and both **Mississippi** and **Kansas** passed minimum mandated benefit laws for mental health disorders this year. Legislation to expand existing parity provisions in **Texas** to include children passed both chambers, but was stalled before the legislation could be enacted. Meanwhile, Congress continues to debate federal legislation that would enact broad-based parity protections for the entire country.

### Involuntary Outpatient Commitment (IOC)

Some mental health groups are working at the state level to enact IOC laws that expand the number of people who can be forced into mental health treatment in a community setting. Although NMHA recognizes that involuntary treatment may sometimes be necessary in an inpatient setting when individuals are a danger to themselves or others, it does not support the use of IOC, in general. NMHA views IOC as a simplistic solution to a complex problem caused mainly by insufficient resources for

community-based services. As the U.S. Surgeon General said, "The need for coercion should be reduced significantly when adequate services are readily accessible to individuals with severe mental illness who pose a threat of danger to themselves or others."

Laws to expand IOC have been enacted in 2001 in **Washington, Nevada, Iowa, West Virginia and Montana**, and bills have been considered in 13 states. In addition, **Mississippi** passed a conservatorship law. At the same time, advocates in other states such as **California and Maryland** have already successfully fought off attempts to enact or expand IOC laws and worked to keep the state's focus on increased resources for voluntary services.

In addition, **Maryland** passed psychiatric advance directives legislation this year. NMHA supports the use of advance directives and believes they can be a way for mental health consumers to plan for their care in the event of a psychiatric crisis. For more information on IOC and advance directives, please call the Advocacy Resource Center at 800-979-NMHA (6642) and select option 6.

### **Olmstead Planning**

Two years have passed since the U.S. Supreme Court decision in the landmark *Olmstead* case, which requires states to provide community services to people with disabilities. And it has been 11 years since the passage of the Americans with Disabilities Act (ADA). Nevertheless, most states are still in the midst of determining how they will implement the mandate to provide community-based services for people with disabilities.

Thirty-seven states have formed task forces to facilitate this planning process, and four states (**Missouri, North Carolina, Ohio and Texas**) have issued final plans that appear to meet recommendations established by the Center for Medicare and Medicaid Services (formerly known as the Health Care Financing Administration).

Although many advocates are frustrated by the slowness of the process, stakeholder groups continue to pressure states to develop inclusive plans that address the specific needs of each disability group. Through consultation with experts in the field, NMHA has developed the following recommendations for Olmstead planning:

- Establish an inclusive planning process with subgroups, including advocates from each disability

group, that address the needs of people with specific disabilities.

- Expand resources to meet demand for community-based services.
- Enact legislation or establish executive orders that make *Olmstead* plans enforceable.
- Focus on specific state institutions and populations to help identify opportunities for community placements.
- Address nursing home placements as well as traditional state institutions.
- Take advantage of opportunities presented by *Olmstead* planning to address the mental health needs of homeless people and those in jails and prisons or at risk of incarceration.

MHAs and other advocates continue to work on a broad scope of issues connected to state and local budgets as well as a host of system reforms, including school-based mental health services, systems of care for children and funding for community-based services. For more information, supportive studies, or strategic consultation in these and other areas, contact NMHA at 800-969-NMHA (6642) or at [shcrinfo@nmha.org](mailto:shcrinfo@nmha.org). Visit our Web site at <http://www.nmha.org>. 

## **Charles Curie Nominated To Head SAMHSA**

Charles Curie, deputy secretary of the Pennsylvania Department of Public Welfare's Office of Mental Health and Substance Abuse Services, has been nominated to be administrator of the U.S. Substance Abuse and Mental Health Services Administration.

Earlier this year, NMHA wrote to the Bush Administration to support Curie's nomination, noting that he will bring to the position an "enlightened public health perspective." Under Curie's leadership, Pennsylvania has won accolades for its managed care system, for community services offered to people with mental health and substance abuse needs, and for efforts to reduce the use of seclusion and restraint in state psychiatric institutions.

The nomination is subject to Senate confirmation.

## Healthcare Reform Resources

NMHA is committed to providing mental health advocates and stakeholders with quality information that helps them promote positive policy changes in states and communities. Below is a list of resources MHAs can use to help support their advocacy efforts. Most of these materials are available on the Internet. If you have problems accessing any of the following items online, contact the Advocacy Resource Center at 800-969-NMHA (6642) and select option 6, or e-mail [shcrinfo@nmha.org](mailto:shcrinfo@nmha.org).

### State Health Care and Health Policy Data Online

From the Kaiser Family Foundation — "State Health Facts Online," available at <http://www.statehealthfact.kff.org>.

### Work Incentives

From the Social Security Administration — "State Chart of Work Incentives Activities," available at <http://www.ssa.gov/work/Beneficiaries/activity2.html>.

### Medicaid

Department of Health and Human Services — "CMS Delays Effective Date of Medicaid Managed Care Rule," available at [http://www.access.gpo.gov/su\\_docs/fedreg/a010618c.html](http://www.access.gpo.gov/su_docs/fedreg/a010618c.html).

From the General Accounting Office — "Health Centers and Rural Clinics: Payments Likely to Be Constrained Under Medicaid's New System," available at [www.gao.gov/cgi-bin/getrpt?gao-01-577](http://www.gao.gov/cgi-bin/getrpt?gao-01-577).

### Children's Health

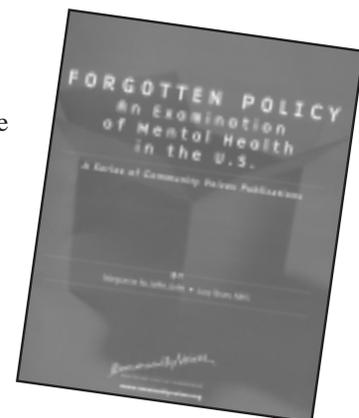
From the Annie E. Casey Foundation — "Kids Count Data Book Online," available at <http://www.aecf.org/kidscount/kc2001>.

### Pharmaceutical Assistance

From the National Governors' Association — "Center Releases Report on State Pharmaceutical Assistance Programs," available at [http://www.nga.org/center/divisions/1,1188,C\\_ISSUE\\_BRIEF^D\\_2013,00.html](http://www.nga.org/center/divisions/1,1188,C_ISSUE_BRIEF^D_2013,00.html).

## New Report Examines Mental Health In the United States

Recent advances in the treatment and understanding of mental health and substance abuse problems notwithstanding, many people continue to receive poor—if any—mental health services. In order to address the needs of the millions of Americans with mental health and substance abuse problems who do not receive appropriate treatment, the W.K. Kellogg Foundation has released *Forgotten Policy: An Examination of Mental Health in the U.S.* This report surveys the barriers to access and utilization of mental health and substance abuse services, and summarizes the financing and coordination of mental health services. It also offers strategies and policy recommendations to improve access to and use of mental health and substance abuse services, especially for underserved populations. To order *Forgotten Policy*, visit <http://www.wkcf.org>.



**NMHA**  
**State Advocacy Update**

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## A Consumer's Perspective on Psychiatric Research

by Shannon Flynn

I have found that consumers participate in psychiatric research for a variety of reasons. Some have altruistic motives—wanting to further biomedical knowledge about their illness or about the efficacy of a certain treatment. The hope of trying a new medication, financial compensation, and greater understanding and control of an illness also motivate psychiatric consumers.

Some of us have a combination of motives. In 1993, I participated in a clinical trial to establish the efficacy of risperidone as compared to clozapine, with the hope of switching medications as a way to remediate severe side effects and avoid the weekly blood tests required with clozapine. I also participated in a 1996 sibling study to help researchers learn more about schizophrenia and for the financial compensation. As a high-functioning consumer in recovery, I feel almost a "duty" to contribute to efforts that will help others who have not been so lucky but have no interest in "greater-than-minimal-risk" protocols.

When consumers think about research, we tend to assume it means medication trials involving potentially risky drug washouts—during which patients go off all medication—and placebo periods. However, much research involves a lower degree of risk, including protocols that offer subjects state-of-the-art evaluations that can help them manage their illness.

I was naturally apprehensive at the outset of the 1993 trial. I wondered if I would be assigned to the riskier arm of the study. As chance would have it, I was in the safer group and it went smoothly. At the time, though, I was convinced my psychiatrist placed me in the less risky arm of the trial. This is a common misperception, but, in fact, group assignment is completely random.

But as consumers we should be aware that research is not treatment. Many protocols may benefit participants, but that is not their primary purpose. The goal of research is the advancement of scientific knowledge. For that reason, well-informed consumers must ask researchers questions before and during the process.

It is also essential to feel safe and know that your participation is completely voluntary. Likewise, you should know that you have the right to leave a study at any time for any reason.

The very nature of mental illness can render us unable to comprehend a protocol's risk-benefit ratio, or cause us to mistrust researchers or to misperceive risk. Thus, it may be appropriate—even necessary—to involve family and friends when considering a research protocol. For example, the support and perspective of my family helped me complete my research trial and switch successfully to a new medication that stabilized me for eight years.

The possibility of relapse and the loss of decision-making ability also worries consumers. Having a durable power of attorney, or DPA, to make decisions on your behalf will ensure that your wishes are accomplished. Also important are advance directives, contracts that allow volunteers to make choices in advance about their participation should their decision-making capacity be hindered.

With the proper protections in place, psychiatric research can be a rewarding experience for us as consumers. As partners with scientists and treatment professionals, we can be proud to be part of the discoveries that may lead to the eradication of mental illness in this century. 



Shannon Flynn is a mental health consumer, a research assistant for the National Institute of Mental Health in the Clinical Brain Disorders Branch, and an art therapist.

Shannon is also a public speaker who educates other consumers about participation in psychiatric research.

### NMHA Puts Children's Mental Health On Its Back-to-School Checklist

With children and families preparing for the new school year, NMHA has kicked off a national media campaign to remind parents, teachers and physicians that mental health plays a critical role in the lives of children and teens. The campaign, part of NMHA's Children's Mental Health Matters initiative, runs through September and includes NMHA's new brochure, "Take a Closer Look." The booklet, which will be available for sale, gives signs and symptoms of children's mental health disorders, offers tips for caring for a child's mental health, and lists resources for parents and teachers. NMHA recently sent public education messages, and event and story ideas to all MHAs to aid their back-to-school media planning. The Children's Mental Health Matters initiative is part of NMHA's Campaign for America's Mental Health and supported by The E.H.A. Foundation, the National Institute of Mental Health and an unrestricted educational grant from McNeil Consumer Healthcare.

### NMHA Adds Resources on Women And Trauma to NCSTAC.org Web Site

NMHA has added a new section to its National Consumer Supporter Technical Assistance Center (NCSTAC) Web site (<http://www.ncstac.org>).

The new section is designed to help empower women who have survived trauma and provides resources on successful women's recovery programs, educational materials, and links to a network of organizations and professionals working on women's mental health issues.

NMHA's NCSTAC was created in 1998 by a grant from the federal Center for Mental Health Services to provide technical assistance to consumer-supporter nonprofit organizations.

### From the MHA Field

*News from NMHA's Nationwide Affiliate Network*

#### Alabama

The **MHA in Morgan County** will hold its 8th annual "Celebration of the Arts and the Mind," on Aug. 18 in Decatur. This theatrical production showcases the creative genius of renowned individuals who struggled with mental health disorders. This year's show will honor author Mark Twain, actress Vivian Vance and Argentine political leader Eva Peron. Vance was a strong NMHA supporter and advocate in the 1960s. More info: contact the MHA at 256-353-1160 or [mhainmc@mhainmc.org](mailto:mhainmc@mhainmc.org).

#### Colorado

The **MHA of Colorado** and the Post-News Charities Fund will host "Tribute 2001: A Night of Mystery and Mental Health," on Oct. 17 in Denver. The dinner will honor two past presidents and current members of the MHA's board of directors, Dr. Bert Furmansky and Cynthia Truitt, Ph.D., who is also a current member of NMHA's board of directors. The dinner will also feature author Stephen White, a *New York Times* best-selling mystery writer. More info: contact the MHA at 303-377-3040.



*Gov. Ruth Ann Minner (far right) and Lt. Gov. John Carney (far left) presented MHA in Delaware representatives Jim Lafferty (second from left) and Diane Treacy with the Delaware Hero award.*

#### Delaware

Gov. Ruth Ann Minner and Lt. Gov. John Carney recognized the **MHA in Delaware** earlier this year as a "Healthy Delaware Hero." The MHA received the honor for promoting and coordinating the mental health objectives of the state's Healthy Delaware 2010 plan, a private and public partnership to improve the health and quality of life for all state residents. More info: call the MHA in Delaware at 302-765-9740 or visit the Healthy Delaware 2010 Web site at <http://www.healthydelaware.com>.

## Senate Committee Passes Parity Bill

*continued from front page*

The HELP Committee modified the legislation during its recent "mark-up" to move it forward, and in the process accepted changes that should insulate the bill from future attack. Most significant, the compromise bill now exempts businesses with up to 50 employees—the original bill would have limited that exemption to companies with up to 25 workers.

The amended legislation also clarifies that, in keeping with the Federal Employees Health Benefits Program, out-of-network mental health benefits are not required to be at parity with other health coverage as long as plan members have reasonable access to in-network providers, and that health plans can manage mental health benefits.

NMHA and its affiliates have thrown their full support behind the bill, and rallied for its passage by contacting members of Congress and attracting Senate cosponsors—but much work remains to be done. For more information about organizing support for the act, see related cover story in the enclosed *State Advocacy Update* (center insert) and call 800-969-NMHA (6642). 📞

## NMHA Welcomes Diverse Leadership to Board of Directors

Representing backgrounds in clinical psychology, psychiatry, nursing, public health, policy and academia, six new members joined the association's board of directors at NMHA's annual meeting in June.

The new members include:

- **State Rep. Garnet Coleman**, vice chair of the Committee on Public Health of the Texas House of Representatives.
- **Sergio Aguilar Gaxiola, M.D., Ph.D.**, project director, Mexican-American Prevalence and Services Survey in Fresno, Calif.
- **Mary S. Harper, R.N., Ph.D.**, geropsychiatric care and research consultant, and distinguished professor of nursing, psychology, community medicine and social work at the University of Alabama in Tuscaloosa.
- **State Sen. Vincent Hughes**, Democratic chair of the Pennsylvania Senate Public Health and Welfare Committee and the Communication and High Technology Committee.
- **Evelyn Lee, Ph.D.**, executive director of Richmond (Calif.) Area Multi-Services, Inc., and clinical professor of psychiatry at the University of California, San Francisco.
- **Nada Stotland, M.D., M.P.H.**, director of psychiatric education for the Advocate North Side Health Network in Chicago and speaker of the Assembly at the American Psychiatric Association. 📞



*Two of NMHA's new board members: Texas state Rep. Garnet Coleman (pictured on top) and Pennsylvania state Sen. Vincent Hughes.*

## A Moment in Mental Health History

Visit the Historic Asylums Web site (<http://www.darkspire.org/asylums/mainpage.html>) for a complete catalog of America's historic state psychiatric hospitals founded in the late 19th century.

Many of the hospitals on the site are based on the architectural theories of Thomas Kirkbride, a 19th century advocate of mental health reform. Most of these facilities no longer serve as hospitals. The site also includes a list of historic psychiatric hospitals in danger of being demolished or permanently altered.



*The Danvers (Massachusetts) State Lunatic Hospital was opened in 1878. Above is the hospital's floor plan, which was based on the so-called "Kirkbride plan."*



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Cited reproductions, comments and suggestions are encouraged.

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## Upcoming Events

### AUGUST

**23-26:** NMHA is a proud sponsor of the Alternatives 2001 Conference in Philadelphia.

### SEPTEMBER

**1-30:** NMHA is a proud sponsor of National Alcohol and Drug Addiction Recovery Month.

**7:** Pennsylvania Healthcare Reform Training.

**20-21:** Rhode Island Healthcare Reform Training.

### OCTOBER

**7-13:** National Mental Illness Awareness Week.

**10:** World Mental Health Day.

**11:** National Depression Screening Day.

For more information about these upcoming events, call 800-969-NMHA (6642) or visit <http://www.nmha.org>.



National Alcohol and Drug Addiction Recovery Month highlights the societal benefits of substance abuse treatment, lauds the contributions of treatment providers and promotes the message that recovery from substance abuse in all its forms is possible. The observance also encourages citizens to take action to help expand and improve the availability of effective substance abuse treatment for those in need.

[www.health.org/recoverymonth](http://www.health.org/recoverymonth)  
**800-729-6686**