



# THE BELM

The newsletter of the National Mental Health Association ■ June 2002

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## Bush Administration Officials To Open NMHA Conference

**CDF President Marian Wright Edelman Featured Speaker**

Key representatives from the Bush administration will kick off NMHA's 2002 Annual Conference in Washington, D.C., June 5-8, under the theme "Prevention, Resilience and Recovery: United for Mental Health." Charles Curie, administrator of the Substance Abuse and Mental Health Services Administration, will lead the opening plenary, "Mental Health is Public Health," along with Peter van Dyck, associate administrator of Maternal and Child Health Bureau, at the Health Resources and Services Administration.



Charles Curie

A special opening night event will honor the affiliate field's tremendous response to the September 11 attacks. Keynote speaker Giselle Stolper, executive director of the MHA in

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Marian Wright Edelman

## Also in this issue . . .

### 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:

- Mental Health Budgets at Risk
- Fight for Parity
- Advance Directives
- Access to Medications
- Healthcare Reform Advocacy Trainings

## Bush Endorses Parity

**Join the "Mental Health Parity Now!" Rally on June 6**

NMHA praises President Bush for his recent endorsement of mental health parity legislation, and for focusing the nation's attention on stigma and health care discrimination. But NMHA also encourages Bush to support a comprehensive parity bill that includes the consumer protections found in the Mental Health Equitable Treatment Act, bipartisan legislation pending in the House and Senate.

"Parity is very much a civil rights issue," said NMHA President and CEO Michael Faenza. "We look forward to working with the president and Congress to enact parity this year, but anything less than comprehensive parity would mean relegating millions of Americans to go without treatment," Faenza said.

To send a clear message to Congress and the public that full parity has powerful and expanding grassroots support, advocates from across the nation will unite June 6 at noon on the grounds of the U.S. Capitol for the "Mental Health Parity Now!" Rally. For more information, visit <http://www.nmha.org>.

For a full analysis of the parity issue, see the *State Advocacy Update* inside this newsletter.

## From the President

Psychological fallout from Sept. 11 and continuing threats of terrorism have tested and refined our concepts of prevention and recovery.



What factors best support consumers in their recovery? What prevention methods produce results? How can people cope when faced with setbacks?

It is these questions—and more—that we will seek to answer when we come together this month to explore strategies for promoting mental health and recovery from mental illness at our annual conference, "Prevention, Resilience and Recovery: United for Mental Health."

But without access to appropriate treatment, recovery remains out of reach for millions of people who need care. The fact is, most Americans lack insurance coverage that would cover access to basic mental health treatment.

To let America know that discrimination against people with mental illness is wrong, conference attendees will join thousands of advocates from across the nation on the steps of the U.S. Capitol to rally for a policy whose time has clearly come—mental health insurance parity.

Together we will see to it that all Americans have access to treatment and care that enhances recovery and helps them achieve their full potential free from stigma and prejudice.

Sincerely,

Michael M. Faenza  
President and CEO

## "Dialogue for Recovery" Sparks Communication Between Doctors and Patients

### *New NMHA Program To Be Distributed Nationwide*

In the not-so-distant past, recovery from mental illness was not thought to be possible. But thanks to medical advances, social supports and therapy, recovery has become a way of life for millions of people with mental illness who return to work, and lead full and productive lives. Yet, many barriers to recovery remain.

One barrier to recovery for people who take medications, particularly antipsychotic medicines, is unpleasant side-effects. For some people, the side-effects are so distressing that they choose to discontinue treatment, which puts them at risk for relapse. Unfortunately, too many physicians are unaware that their patients struggle in such discomfort. To help consumers and doctors communicate more effectively and work together to find practical treatment alternatives, NMHA created a new program called "Dialogue for Recovery."

The program relies on several resources to enhance consumer-doctor relationships. It includes a toolkit and video detailing productive two-way communication, or a "Dialogue for Recovery," between consumers and their physicians. "If the doctor doesn't listen to you, find another one," says Lee, a consumer featured in the video. He examines the important role that consumer-physician relationships can play during recovery.

Dialogue for Recovery stresses that troublesome side-effects don't have to be a part of recovery. "Let your doctor know that this isn't acceptable," Lee explains on the video. "Don't accept the side effects." Lee also tells

consumers that being on a new antipsychotic medication was like "coming out of a coma."

A key component of the program, the "Antipsychotic

Side-Effects Checklist," or ASC, is designed to help consumers and their doctors easily identify and communicate about medication side-effects, so they can determine which are the most bothersome and whether to modify the treatment. The ASC checklist includes common and distressing medication side-effects such as loss of energy, sleeping too much, feeling restless or jittery, drooling, having memory and concentration problems, and a lack of sex drive. Dialogue for Recovery also encourages consumers to discuss other quality-of-life issues with their providers, such as housing, employment and social support.

In addition, the program features a patient brochure and offers a quick-reference wallet card on how to discuss side-effects with physicians. Materials for physicians include a similar fact sheet. A "family and friends" fact sheet details ways they can offer support to a loved one diagnosed with a serious mental illness. The program will be distributed nationwide to mental health consumers and professionals, physicians, family members and advocates through NMHA's nationwide affiliate network.



## Leaders in Recovery Discuss Their Lives and Work

Laurie Ahern and Daniel Fisher M.D., Ph.D., founders and co-directors of the National Empowerment Center and pioneers in recovery from mental illness, share their thoughts with *The Bell* about their lives and work as advocates. Ahern and Fisher will receive the 2002 Clifford W. Beers Award, NMHA's most prestigious award, at NMHA's Annual Conference June 5-8 in Washington, D.C.

**The Bell:** *Would you tell us a bit about your experiences with mental illness?*

**Laurie:** I was diagnosed with schizophrenia when I was in college at age 19. I was hospitalized, frightened and alone. With my diagnosis came a prophecy of doom that my life would be very limited, and that I shouldn't expect much in the way of a career or dreams.

**Dan:** I was diagnosed with schizophrenia at 24 and also told I would probably have it for the rest of my life. At the time, I was working in the neurochemistry lab at NIMH, and felt like my career was coming to a close just as it was beginning.

**The Bell:** *Yet you both defied your prognoses and recovered to embark on meaningful and successful careers. Tell us about your early work and how going public with your illnesses affected it.*

**Laurie:** I became a newspaper reporter and editor and didn't disclose my history until later out of basic necessity. With the stigma that surrounds mental illness, I wouldn't have been hired as a journalist. But once I did make the choice to go public and become an advocate, I knew it meant the end of my newspaper career.

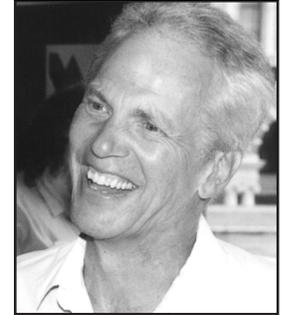
**Dan:** I decided to become a psychiatrist after my second hospitalization. I wanted to reform the system but was advised not to disclose my history during residency. I did so afterward, and it severely limited my job opportunities—not just my disclosure, but my advocacy on behalf of consumers. In fact, I'm often characterized as “too consumer friendly.”

**The Bell:** *What specifically led to your careers as advocates?*

**Laurie:** I was fortunate enough to recover from my illness, but when I looked around me, I saw so many



Laurie Ahern



Daniel Fisher, M.D., Ph.D.

other people who hadn't had the same opportunity. I had people around me who believed I could get better—and that was key. Also, I once covered a story on a state hospital where the big issue was whether to let people go outside, because there were schools nearby. It was so poignant to me that I could be one of those people locked up in a hospital trying to get out. When I had the chance to work at the Center, I felt it was my life's calling.

**Dan:** When I was hospitalized, I kept thinking that if they knew what I really needed, they'd interact with me in a much more positive fashion. I needed hope, I needed to be treated as a human being, I needed tools to recover. And I was outraged at the punishing aspects of treatment. I felt there needed to be a more human and informed approach.

**The Bell:** *And so 10 years ago you started the National Empowerment Center. How did it get off the ground and what is its goal?*

**Dan:** We got the Center going through a CMHS grant to start a consumer supporter technical assistance center. Our goal from the beginning has been to get the message out that people can recover. And who knows better what can help or hurt people in recovery than people who have gone through the experience themselves? We want to transform the way mental healthcare is provided in all sectors of society. There needs to be a shift in understanding about recovery.

**The Bell:** *What is your shared philosophy on recovery?*

**Laurie:** We believe that mental illness is simply a label for the severe but temporary emotional distress that interrupts a person's role in society. We lose our social roles when we're labeled with mental illness, but we can recapture our dreams and dignity through self-determination and the absence of coercion.

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Laurie and Dan lecture around the country and give workshops to consumers, ex-patients, practitioners and family members. Their empowerment and recovery manuals have been translated into six languages.

In addition to their advocacy work at the NEC, Laurie Ahern is vice president of the National Association of Rights and Protection Advocacy, and Daniel Fisher, M.D., Ph.D., works as staff psychiatrist at Eastern Middlesex Outpatient Center in Wakefield, Mass.

## MHA in Los Angeles County

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## The Village Offers “Designed Care” Approach to Service

The African proverb, “It takes a village to raise a child,” could easily be applied to the coordinated and multidisciplinary team approach of the Village Integrated Service Agency, a program of the MHA of Los Angeles. Touted for its “designed care” service, the program has achieved great success for its individualized approach that helps support people with serious mental illness in their recovery. “We think that one size does not fit all,” says Village director Martha Long.

### 2002 Innovation in Programming Award Winner

Presented to recognize innovative and effective Mental Health Association programs.

The Village began in 1990 as a California Department of Mental Health pilot project. Consumers and family members were part of the task force that designed the model: a delivery system built on an integrated service approach with capitated funding. The program's dual mission, Long says, is to “support and teach adults with serious mental illness to recognize their strengths and power to live, socialize, learn and work in the community, and to stimulate and promote systemwide changes so these individuals may achieve these goals.”

The Village, which became a permanent program in 1996 and is now funded on the county level, serves nearly 500 members. The *Los Angeles Daily Journal* praised the program as one that “revolutionizes recovery.”

“We are involved with people's entire lives and not just their mental illness,” explains Long. For example, when someone who is homeless or right out of jail enters the program, the Village asks what would make that person's life better. “It may not be mental health,” says Long. “We deal with a lot of people who are not treatment resistant but may be clinic resistant and unable to deal with bureaucracy. If you offer them human help, it builds trust.”

Members are free to choose from a full menu of services, including ones that focus on employment, housing, social skills, legal needs, substance abuse, education, finances, physical health and medication. All members of the Village are assigned to a multidisciplinary team. Each team is made up of a full-time psychiatrist, psychiatric

nurse, licensed clinical social worker and four psychosocial specialists. Members also have a personal service coordinator, who helps them identify and pursue their goals. Resource specialists in employment, recreation, money management and substance abuse recovery complement the teams.

The Village uses a “collaborative psychiatry” approach to providing treatment, which means that clients are actively involved in the decision-making for their treatment. Clients are made aware of their options, and can indicate their individual preferences and goals.

Continuity of care is another important aspect of the program, Long says. If members need to be hospitalized, the Village psychiatrist serves as the admitting, treating and discharging physician, which minimizes disruption in members' treatment—and in their lives.

Long stresses that one of the greatest lessons learned for the Village is the success of its policy not to disenroll clients. “The relationship between members and staff is based on trust,” says Long. “The members know that they are not going to be kicked out. Our commitment to them is permanent. Staff know that if a certain approach or medication doesn't work, they have to keep trying to find something that does.”

The Village has also learned that having a mobile staff greatly increases the success of individual treatment. “The burden on family is reduced,” says Long. “Our ongoing commitment to individuals helps make the system more effective and reduces gaps in service.”

The Village is an NMHA Partners in CARE program. MHAs and other organizations in five states are replicating the Village in their communities through SAMHSA's Community Action Grant program. In 2000, the American Psychiatric Association honored the MHA Village with the Gold Achievement Award for making a difference in the lives of people with serious mental illness. 



*MHA of Los Angeles County's Village ISA program provides job training and other community-based, integrated services for people with mental illnesses. Ricardo Perez (pictured above) works at the Village's Deli 456, a successful catering business in Long Beach. For more information on Deli 456, call 562-590-8790.*

# NMHA and CWLA Partner To Improve Children's Mental Health

by Shay Bilchik, president and CEO, Child Welfare League of America



Although public awareness of children's mental health in our nation has increased in recent years—largely through advocacy by NMHA and other organizations—the full range and extent of children's needs is not understood.

The high school shootings in Columbine and Paducah, a decade of skyrocketing rates in youth suicide, and the escalating phenomena of bullying and teasing in our schools have all contributed to an increased awareness of children's mental health issues. In addition, the ability to identify and treat mental health disorders in young children has improved our understanding and acceptance of such problems. But while these efforts and events have opened our eyes in America, they have not moved us to meaningful action. For this reason, CWLA has redoubled its efforts to expand public education and advocacy to improve the mental health and well-being of our nation's children.

CWLA's first priority has been to increase this country's focus on the need for improved mental health services for children in out-of-home care. These children cope not only with the events that led to their entry into care, but also the personal grief and trauma that accompany the loss of their families. In addition, multiple placements, separation from siblings and inadequate treatment often exacerbate already difficult situations. An estimated 80-85 percent of the more than 500,000 children in foster care in the United States have an emotional or substance use disorder. A recent survey of CWLA's more than 1,170 public and private member agencies revealed that behavioral health is a primary need and concern of child- and youth-serving organizations nationwide.

In response to this need, a coalition of 30 consumer and professional organizations involved with children and families—led by the American Academy of Child and Adolescent Psychiatrists (AACAP) and CWLA, and including NMHA—began an initiative last March to improve the design, delivery, and outcomes of the mental health and substance use services and supports provided to children in foster care and their families.

The coalition has drafted a set of values and principles to improve policies and practices in the systems that serve these children and their families. The coalition also developed a policy statement on screening and assessment. In turn, this should lead to other reforms in how local communities and the formal systems intersect around mental health, substance use, and child welfare issues to ensure and promote the well-being of children. We are also compiling an evidence-based assessment toolkit, which incorporates values and principles to help guide the screening and assessment process for children in the foster care system who are at risk for developing mental health problems. The toolkit will suggest how different systems and practitioners can meet the service needs of children. In addition, the coalition is creating a research and policy agenda to promote understanding about young children's mental health and the programs that meet their needs.

The coalition and CWLA's partnership with NMHA are just the beginnings of a larger movement to support our children and their right to a safe and nurturing childhood. Together, we will make sure that our shared vision to improve children's mental health services becomes a reality. ■

*The CWLA is the oldest and largest nonprofit organization developing and promoting policies and programs to protect America's children and strengthen America's families.*

## From the Field

### *News from NMHA's Affiliates*

#### New Jersey

The **MHA in New Jersey's** Consumer Connections program, which aims to expand employment services for people with mental illnesses, is in the midst of its annual consumer-training program. The MHA will hold a "Job Search 101" training June 4 and 11, and an "Engaging the Hard to Engage" training June 19. That training will focus on situations that pose barriers to effective clinical work. Other trainings held

earlier in the year included "So You Want to Be a Consumer Provider," "Core Training" and "Non-Violent Crisis Intervention." More info: Contact the MHA at 973-571-4100.

#### North Carolina

The **MHA in Forsyth County, Inc.**, hosted a panel discussion on the book and movie "A Beautiful Mind" to help educate the Winston-Salem community about mental illness and media portrayals of people with mental disorders. More info: Contact the MHA at 336-759-9370 or visit <http://www.mha-fc.org>.

## Advocacy Spares Juvenile Offenders With Mental Illness

In the past year, NMHA, mental health associations and other advocacy organizations have convinced state governors, pardon boards and courts to temporarily stay the executions of one adult and three juvenile offenders with mental illnesses. A fourth juvenile offender's sentence was commuted to life in prison following similar appeals by NMHA and other advocates.

"No one denies the horrendous nature of their crimes, but execution should not be the consequence of juvenile crime, particularly when the person is known to have a serious mental illness," said NMHA President and CEO Michael Faenza.

The National Coalition to Abolish the Death Penalty estimates that up to 10 percent of people on death rows throughout the country have serious mental illnesses. Since 1976, state governments have put 18 people—including four in 2000—to death for crimes they committed as juveniles despite histories of abuse, severe mental illness and psychological trauma.

"Congress established the juvenile justice system because youth should not be judged and punished by the same standards as adults," Faenza said, "and people with serious mental illnesses should not be held to the same standard of culpability and accountability for their actions."

In an attempt to stem the rise in such executions, NMHA's Board of Directors last year called on states to "suspend using the death penalty until more just, accurate and systematic ways of determining and considering a defendant's mental status are developed." NMHA believes that the age, maturity, mental status and any childhood history of abuse of a youthful offender should be mitigating factors in deciding an individual's punishment (see NMHA's position statement at <http://www.nmha.org/position/deathpenalty/deathpenalty.cfm>).

Over the last decade, the United States has executed more offenders of juvenile crime than the rest of the world's nations combined, in defiance of several international laws. The death penalty for juvenile offenders is expressly prohibited by the International Covenant on Civil and Political Rights, the American Convention on Human Rights and the U.N. Convention on the Rights of the Child.

## Bush Officials to Kick Off NMHA Conference

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New York City, will describe the emergency mental health services provided to New Yorkers and ongoing efforts to support those still struggling in the aftermath.

A congressional affairs briefing on the first day of the conference will equip attendees with all the information they need for NMHA's day of advocacy on Capitol Hill. Affiliate leaders, Congressional staff and NMHA representatives will cover comprehensive mental health parity, Medicare, juvenile justice, consumer programs, appropriations and housing.

The second plenary, "Recovery: Raising the Bar," will feature William Anthony, Ph.D., executive director of the Center for Psychiatric Rehabilitation at Boston University; Jacki McKinney, co-founder of the National People of Color Consumer/Survivor Network; and Mark Ragins, M.D., founding staff member and community psychiatrist for The Village Integrated Service Agency in Los Angeles. This session will stress the reality of recovery and resilience for people with mental illness and co-occurring disorders.

The need for resilience-building and early intervention to promote mental health across the lifespan—and in all populations—will be the focus of the final plenary, "Prevention: A Community Expectation." This thought-provoking session will be led by Ronald Kessler, Ph.D., professor of health care policy at Harvard Medical School, and William R. Beardslee, M.D., psychiatrist-in-chief at Children's Hospital in Boston.

The 2002 Media Awards luncheon will honor journalists and other media professionals for their outstanding coverage of mental health issues in television, newspapers, radio and photography.

A special closing night dinner will honor founder and president of the Children's Defense Fund Marian Wright Edelman, who will receive NMHA's Tipper Gore "Remember the Children" Award and speak about her advocacy work.

The dinner will also feature the presentation of the prestigious Clifford W. Beers Award and give attendees a chance to hear from this year's winners, Laurie Ahern and Dan Fisher, M.D., Ph.D., co-founders of the National Empowerment Center.

Throughout the conference, consumers, advocates, mental health practitioners and policymakers will take part in more than 35 workshops exploring strategies to promote mental health and recovery from mental illness. The sessions will also cover a variety of other topics, including "Cultural Competency in Mental Health Advocacy and Education," "Integrating Consumer Providers into a State Mental Health System" and "Responding to Crises: Lessons from the Field." 

*For more information about NMHA's 2002 Annual Conference, call 800-969-NMHA (6642) or visit <http://www.nmha.org>.*

# Recovery Advocates Share Beers Award

*continued from page 3*

People are empowered to recover when they are entrusted to make decisions about their lives, and when they have positive peer support and relationships.

**Dan:** Our lives echo what most people who recover know to be true: that it is vital to have trusting relationships with people who believe in you and your ability to recover. All these values are embodied in our recovery model called PACE, or Personal Assistance in Community Existence.

**The Bell:** *How have your ideas about recovery changed over time?*

**Laurie:** Our ideas have become more clarified. Ten years ago we weren't talking about full recovery as we are now.

We also know that people are more than their biology and their chemistry. We're trying harder to focus on the whole person, whole lives and dreams—mental illness is as much a loss of dreams as a loss of dopamine.

**The Bell:** *What are your thoughts on plans to cut funding for your and other technical assistance centers next year?*

**Dan:** We are hopeful that funding will be restored for 2003, and that people see value in peer-support, self-help and promoting recovery—and successful outcomes. In the long run, a little bit of funding provides a tremendous amount of support. It doesn't cost a lot of money to give people hope. 

## NMHA Educates Health Reporters About PTSD

It was widely reported that the Sept. 11 terrorist attacks traumatized people across the country, but it is less well known that millions of Americans experience debilitating trauma every day. To help the media understand the frequency and impact of trauma, NMHA sponsored a symposium last month in New York City called “Beyond 9/11: Exploring Trauma in America.”

At least 50 percent of Americans will experience at least one traumatic event in their lives, such as a natural disaster or assault, according to Matthew Friedman, M.D., Ph.D., executive director of the National Center for Post-Traumatic Stress Disorder, who spoke at the symposium. And an estimated 5.2 million people between the ages of 18 and 54 have PTSD, according to the National Institute of Mental Health.

### Marla Hanson's Story

Despite the high rates of PTSD, most people don't get treatment, experts at the briefing agreed. And the result of untreated PTSD can be devastating. Model Marla Hanson, who spoke at the meeting about her experience with PTSD after an assault in the late 1980s, developed the disorder 10 years after the attack.

Memories of the assault came back with such force that it “obliterated life as I knew it. Images returned to haunt my dreams making it hard to sleep, and they would return to invade my thoughts during the day,” Hanson, whose face was slashed during the assault, told the audience.

On a bus to visit a friend in Rhode Island, a then suicidal Hanson sat next to a passenger—a Vietnam veteran—who asked if she had PTSD as a result of the attack. “As the veteran spoke to me about the symptoms of PTSD, an

intense relief flooded over me. I simply had a disorder ... and I didn't have to kill myself.”

Hanson sought treatment, psychotherapy and antidepressant medication, and has since recovered. “Recovery is not some abstract thing that happens when the requisite time passes, but something that is tangible and achievable with the right help,” said Hanson.

### The Facts About PTSD

Immediately following a traumatic event, most people experience symptoms that are similar to those of PTSD, including reoccurring thoughts of the event and avoidance of similar situations.

However, not everyone who experiences a traumatic event goes on to develop PTSD. Symptoms must persist for at least a month for a person to be diagnosed with PTSD, Friedman noted. Risk factors include the severity and type of event, prior experience with traumatic events and a person's unique biological response to physical stress, said Rachel Yehuda, M.D., professor of psychiatry and director of the Post Traumatic Studies Division at Mt. Sinai School of Medicine and the Bronx Veterans Affairs Medical Center.

The media can help raise awareness of PTSD as a real and common illness, said Barbara Rothbaum, M.D., associate professor of psychiatry and director of the Trauma and Anxiety Recovery Program at Emory University in Atlanta. What is important is getting the information out there, Rothbaum said, because “with diagnosis and treatment ... there's hope.”

The symposium was made possible by an unrestricted educational grant from GlaxoSmithKline.



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*The Bell* is published by the National Mental Health Association, which works with more than 340 affiliates nationwide to promote mental health, prevent mental disorders and achieve victory over mental illnesses through advocacy, education, research and service.

To join NMHA and receive *The Bell*, visit NMHA's Web site at <http://www.nmha.org> or call 800-969-NMHA (6642).

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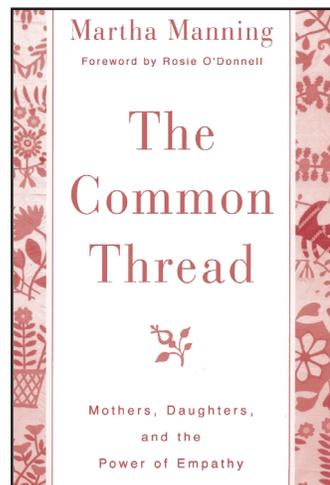
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- 36 states will elect or re-elect governors.
- 34 states will elect or re-elect U.S. Senators.
- 50 states will elect or re-elect all 435 members of the U.S. House of Representatives.

Call NMHA's Voter Empowerment Project at 800-969-NMHA (6642).

## Advocacy Begins at the Ballot Box

## Available Now



## The Common Thread

by Martha Manning

with a forward by Rosie O'Donnell

Critically acclaimed author and psychologist Martha

Manning offers mothers and daughters of all ages a new way to understand each other. In her book, Dr. Manning focuses on one factor: empathy, which she calls the "mortar" in the bond between mother and daughter. *The Common Thread* is now available at all bookstores. For more information on Dr. Manning's book tour, call 212-207-7860.