Catalyst
TREATMENT ADVOCACY CENTER
www.psychlaws.org

Why TAC exists: Looking back five years

by Treatment Advocacy Center President E. Fuller Torrey, M.D.

Five years ago, Mr. and Mrs. Theodore Stanley asked me whether anything could be done to help the large number of individuals with severe psychiatric disorders who were living on the streets, incarcerated in jails, and regularly being victimized. I answered that the treatment system was broken, in part because misguided civil libertarians had turned brain diseases into a civil rights issue. Individuals with severe psychiatric disorders had essentially been kidnapped by lawyers.

The Stanleys then generously agreed to partially fund a modest effort to improve the treatment system that emerged as the Treatment Advocacy Center. Friends and colleagues said that it would be a quixotic fight for five reasons: civil libertarian lawyers were well funded, antipsychiatry groups would oppose us, theoretical allies would not join us because we were not “politically correct,” state legislators would not listen, and supporters would not donate the matching funds we needed to survive.

> **“Until we find the causes and definitive treatments for schizophrenia and bipolar disorder, we have an obligation to those who are suffering to try to improve their lives.”**

Five years later, it is clear that my friends were correct regarding the first three reasons but wrong on the last two. State legislators have listened, and this has resulted in important changes in treatment laws in California, Idaho, Illinois, Maryland, Minnesota, Montana, Nevada, New York, North Dakota, South Dakota, Utah, Washington, West Virginia, Wisconsin, and Wyoming. Many of the individuals Mr. and Mrs. Stanley wished to help are receiving treatment today because of changes in state laws brought about by TAC’s efforts.

Supporters have also been extraordinarily generous in donating the matching funds we need to survive, and TAC has even modestly grown in size. These donations are often accompanied by passionate letters of support, making it clear that we are not alone in this fight.

Personally, helping to start TAC has been one of the most satisfying things I have done in my life. Until we find the causes and definitive treatments for schizophrenia and bipolar disorder, we have an obligation to those who are suffering to try to improve their lives. Except for biological chance, any one of us might today be there, living on the streets or in jail. TAC is the only organization willing to take on this fight, and I am very proud to be part of it.

And we are just getting warmed up.

The Treatment Advocacy Center is celebrating its five year anniversary! This special issue of *Catalyst* launches our new look with a snapshot of the past five years – in the legislatures, in the courts, in research, and in homes across America. This issue is dedicated to all those who are suffering and their advocates, people who are passionate about reform, who refuse to give up, who fight the status quo. People like you.

SUMMER/FALL 2003

Legislation: 5 years, 16 laws...............2
Advocacy: Lessons learned................4
The Courts: Major decisions.............11
Research: AOT successes................14
Memorials and Tributes.....................15

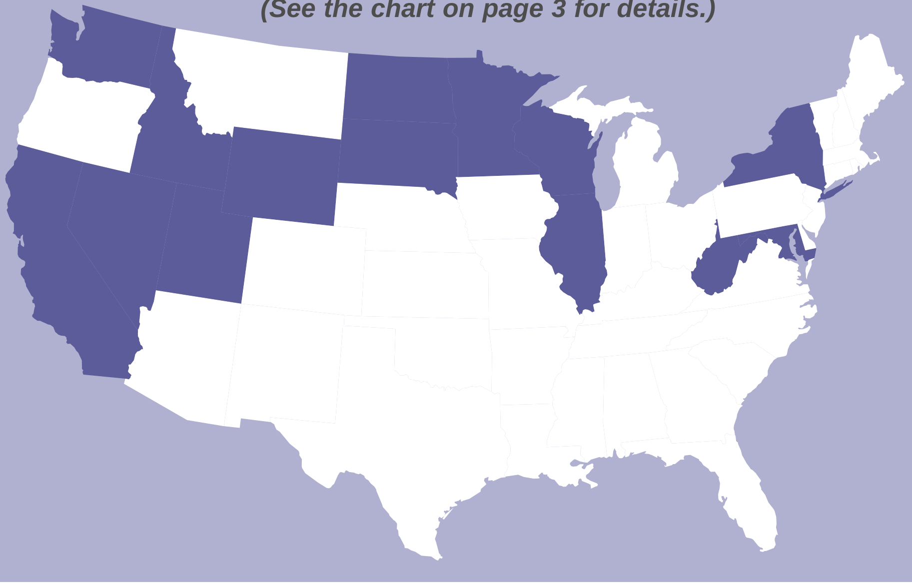
Legislation

Swinging the pendulum back to the center

The Treatment Advocacy Center works to increase awareness of issues surrounding lack of treatment and promotes laws that support assisted outpatient treatment and standards for commitment based on need for treatment over dangerousness. Since 1998, sixteen states (and one Canadian province) have made legislative changes that have improved treatment laws, some to an extraordinary degree, some incrementally.

States that have revised their laws since April 1998

(See the chart on page 3 for details.)



Catalyst

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About TAC

The Treatment Advocacy Center (TAC) is a national nonprofit organization dedicated to eliminating legal and clinical barriers to timely and humane treatment for millions of Americans with severe brain disorders who are not receiving appropriate medical care.

Since 1998, the Treatment Advocacy Center has served as a catalyst to achieve proper balance in judicial and legislative decisions that affect the lives of people with serious brain disorders. TAC works on the national, state, and local levels to decrease homelessness, incarceration, suicide, victimization, violence and other devastating consequences caused by lack of treatment.

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Summer/Fall 2003, special anniversary issue

Changes in treatment legislation, last 5 years

There have been many legislative successes in the last five years - but there is still much work to be done. Today, nine states still offer NO option for assisted outpatient treatment. And about half of states require dangerousness before the courts can intervene. So even as we celebrate successes like these, work continues.

State	Date Passed	Description
Wyoming	March 1999	Revised treatment standard, now considers probability of destabilization.
Nevada	May 1999	Now considers past treatment history to determine probability of harm.
New York	August 1999	Kendra’s Law - assisted outpatient treatment; revised treatment standard.
South Dakota	February 2000	Revised treatment standard, considers past treatment history.
Ontario	June 2000	Brian’s Law - allows community treatment orders.
Washington	April 2001	Requires great weight be given to evidence of prior history of pattern of decompensation and discontinuation of treatment.
Montana	April 2001	Clarifies assisted outpatient treatment and other provisions
West Virginia	May 2001	Revised treatment standard; voluntary treatment agreement; consideration of previous history.
Wisconsin	September 2001	Maintained progressive treatment standard beyond sunset date.
California	October 2001	Consideration of prior history and mandated consideration of family member testimony.
Minnesota	June 2001	Revised treatment standard, need treatment to prevent deterioration.
Idaho	March 2002	Revised treatment standard modifies “gravely disabled” from “essential needs” to “basic needs.”
California	September 2002	Laura’s Law - assisted outpatient treatment; revised treatment standard.
Utah	March 2003	Revised treatment standard. Danger no longer need be “immediate” and includes the substantial risk of “protracted loss or impairment of the function of ... mental faculty.” Considers historical information.
North Dakota	April 2003	Revised treatment standard.
Maryland	May 2003	Modifies emergency evaluation criteria, “imminent” dangerousness no longer required.
Illinois	Summer 2003	Revised treatment standard, includes consideration of prior history.

Advocacy

People often ask us how to change their state's treatment law. Our publications and website offer many tips and ideas. But we thought that for this special anniversary edition of *Catalyst*, we would call on the real experts - some of the many people across the country who have been instrumental in successfully changing their state laws.

Every state and situation is different. Sometimes these stories offer conflicting advice – for instance, one person suggests commissions are useless, another recounts how a commission in his state made all the difference. Other basic tenets seem to hold true in all cases – like preparing materials in advance and not being shy about talking to the media.

Today, advocates across the nation are fighting battles from their statehouses to their courthouses to secure better laws for people who are the most ill. Learning from one another's experiences, good and bad, can be a powerful way to accelerate change.

A SCHOLAR AND PSYCHIATRIST:

Things I have learned in changing civil commitment laws

by Darold Treffert, M.D.

Dr. Treffert, a Wisconsin psychiatrist, has been a tireless advocate for reform of his state's treatment law. He coined the term "dying with their rights on" and was among the first to begin cataloguing preventable tragedies – his vision inspired TAC's database at www.psychlaws.org/ep.asp. His work in passing a landmark law in Wisconsin has reverberated through the nation. Here he offers advice on what worked in his legislative battles.

Real life instances help

Civil libertarians hate them because they clutter up, with glaring and irrefutable reality, what they would prefer to be philosophical debates about free will, police powers and *parens patriae*. Legislators understand, and relate to such 'anecdotes' (as opponents dismissively refer to them) because they put a real, live face and human price on the tragedies that ensue from non-action. Witness [New York's] Kendra's Law, [California's] Laura's Law, and others that have emerged after (regrettably) some tragedy. In Wisconsin, the Onalaska shootings of a priest and three parishioners by an obviously ill man whose family had vainly tried to help before that tragedy was persuasive evidence for change. Such instances provide compelling, real-life (and death) evidence of need for thoughtful deliberation, and then, change.

The public can be more persuasive than professionals

Professionals can certainly use their expertise to help define and explain the problem, and even help craft remedies. But in the legislative arena where these battles are fought, letters, testimony and phone calls from families and friends, and concerned groups like NAMI, trying to exercise a simple 'right to be rescued' over a 'right to be sick' for persons they care deeply about, are more persuasive and influential than professional testimony alone. The most effective strategy is a combined effort of families, friends and a concerned public with knowledgeable, down to earth, articulate, and equally concerned professionals.

Stereotypes persist

"Warehouses," "One Flew over the Cuckoo's Nest,","locking people up," and other outdated stereotypes about psychiatric facilities and treatment continue to exist, and be promoted, by opponents of civil commitment reform in spite of overwhelming evidence to the contrary regarding modern-day treatment and programs, the vast majority of which are out-patient, not in-patient, and short-term, not long-term.

Persistence pays

Like the wheels of justice, the wheels of legislative change grind slowly also. It was 12 years, and several legislative sessions, before [Wisconsin's progressive treatment standard] the "Fifth Standard" finally became law in 1996. But even that long delay was not wasted time in that during those years hearings and other publicity and discussions took place that gave the issues involved necessary visibility and debate. In that interim, other innovations occurred beyond enacting the law itself, such as settlement agreements, and improved local programming for chronic mentally ill persons. But such delays entail multiple meetings, waiting your turn at lengthy hearings, enduring stereotyping and a willingness to compromise to accomplish significant changes. But it is well worth the effort once successfully completed.

A MOTHER AND FIRST-TIME ADVOCATE:

What I learned when we took on the legislature – and won

by Sheree Spear

Sheree Spear had never set foot inside a capitol building and knew little of the legislative process. What began in November 2002 as a one-person, dining room table, letter-writing campaign ended eight months later in a bill with the Governor's signature. A tenacious first-time advocate, here she shares some lessons she learned.

Getting this law passed was one of the most stressful, challenging, and rewarding experiences I've had.

My passion for changing North Dakota's treatment law came from my inability to get my son in for even a 24-hour psychiatric evaluation when we could all see he was suicidal, paranoid, and delusional. We were repeatedly told we couldn't get him help because we couldn't prove he was dangerous.

My passion also comes from seeing the inner pain my son lived with. And from watching how the paranoid ideations prevented him from voluntarily accepting the very treatment that would free him. Here's how he describes the experience of having schizophrenia and not getting proper treatment:"I know now that there is a heaven and a hell. And they are here on earth. Because what is constant pain and suffering? That's hell. That's where I'm at. And I can see heaven here, just as clearly as I can see you sitting there. And I watch other people living in it. But I can't get there."

> **"Those who think their life is untouched by untreated mental illness may be surprised to learn all North Dakota residents will chip in to pay a half million dollars or more to house Jeffrey Scott in the Bismarck prison. He was sentenced in December to 20 years for shooting his mother's fiancee ... His family had tried for years to get him help for his mental illness."**
>
> **– Sheree Spear, *The Forum* (Fargo, North Dakota), Feb. 26, 2003**

Use personal stories to educate

Many people will not care about the issue unless they first hear personal stories. Early on, a legislator opposed to our bill set up what turned out to be an informal hearing. I thought I was meeting with two or three people, but when I walked in, nine legislators were seated around the table and opposition groups had been invited and sat against the wall.

I was asked to "immediately get to the exact words in the law I wanted changed." Instead, I said, "Before I get into specific language, I'd like to make a 1-2 minute opening statement." I knew they would split hairs and not care about why the law needed to be changed unless they heard personal stories first.

Make your case in two minutes

It helped me to have a 2-minute, memorized, compelling, logical spiel that condensed: a personal story, the extensive legal research supporting the change, national trends and tragedies, and names of supportive groups. Why 2 minutes? That is about the most time I could expect from a legislator passing by on their way into or out of session.

Create materials that make your case

I created a visual map of the commitment process that was effective in quickly showing that the proposed language would not change the process in any way. The many safeguards in place to protect people's rights would not be compromised. I learned that opponents would try to kill a bill simply by creating enough doubt. If they could do that, they wouldn't even need to supply concrete reasoning for their position. To counter that, I explained the current commitment process and criteria for involuntary treatment and how these create a gap in the law that results in tragedies.

It turned out that educating people was my primary job and one of the most significant keys to gaining support.

Use available materials and research

You don't have to create everything from scratch. The extensive legal research the Treatment Advocacy Center provided was the solid footing supporters needed to confidently attach their name and reputation to the bill. The personal stories are needed, but they are not enough.

Legislators need to know proposed legislation has been thoroughly examined from every aspect, including issues of civil rights, due process, and constitutionality. What other states are doing and why is critical information.

Get stakeholder input

I never wanted this to be 'Sheree's bill', even though moving it forward was my personal project. I sincerely wanted stakeholders across the state, in all areas, to have input. I made that clear

continued on page 6

in all my meetings - from presentations to the Police Chief's Association and the Sheriff's Association to one-on-one meetings with states attorneys, mental health workers, consumers, and family members. Their input made the resulting bill better.

Remember that passion is the ultimate power

While still in the early, letter-writing stage, my boss offered to do anything to help me. I said, "Well, do you know anyone who is really powerful?" He looked at me awhile and then said, "You are the most powerful person I know."

I was stunned. It was so profound and totally challenged my perspective. I not only remembered his words through this tough process, but will remember them for life.

I believe the informal hearing I mentioned earlier was an attempt at intimidation and an effort to kill the bill before it ever got off the ground. Instead of the intended affect, here's what I thought afterward: In this situation, these people have the power and I don't. But that kind of power can come and go. My passion will outlast their power.

Probably the most important thing I learned is that personal passion, directed constructively, is very powerful indeed.

A LEGISLATOR WITH A PERSONAL STAKE:

Lessons learned in reforming Minnesota law

by Mindy Greiling

Minnesota State Representative Mindy Greiling's personal experiences led her to sponsor SF179, which removed the requirement that danger be "imminent" for emergency response, and improved the standard for treatment so that a person's deteriorating psychiatric condition could be considered. The law also allows lengthened hospital stays to stabilize a person's condition as well as timely intervention with medication. The new law became effective July 2002. She shared some strategies that worked in Minnesota.

Try for leaders with mental illness in their families

They have first-hand experience and are strongly motivated. When our son ran into Minnesota's restrictive civil commitment laws, I was as enraged as a mother bear whose young is threatened – and terribly fortunate to be a state legislator myself.

> **When our son ran into Minnesota's restrictive civil commitment laws, I was as enraged as a mother bear whose young is threatened – and terribly fortunate to be a state legislator myself.**

Join forces with others with personal stories they will openly share

After our family story appeared on the front page of both Twin Cities newspapers, I was deluged with calls and visits from such folks, including capitol insiders. Former Senator John Milton became a soulmate in this battle. I started a database and used it for the duration. Definitely work bipartisanly.

Use professional expertise/research

A key ally was Dr. Charles Schulz, Chair of our University of Minnesota Department of Psychiatry. He pointed out that treatment lags result in poorer responses, and that even the most ideal treatments cannot help if the patient isn't there.

Work closely with TAC's staff

I was usually able to connect with them more successfully than folks in Minnesota and received terrific materials. Their Model Act booklet quelled many foes' best arguments.

Organize a coalition larger than the opponents'

Ours consisted of: AFSCME, League of Women Voters, the Medical Association, Psychiatric Society, National Alliance for the Mentally Ill, and the State Advisory Council on Mental Health. We neutralized many other groups, some who originally opposed us.

Employ the powerful forces of the media whenever possible

Mainstream public opinion is with us. We were blessed with an incredible editorial writer, Kate Stanley, who penned a plethora of supportive columns in the *Minneapolis Star Tribune*. She more than earned an award for her efforts, presented by NAMI at last year's national convention.

Don't let your guard down after the legislation is passed

Opponents will be back to try to gut your changes and also impede implementation.

AN ADVOCATE:

What worked in New York in passing Kendra’s Law

by D.J. Jaffe

D.J. Jaffe, a family member and a board member of the Treatment Advocacy Center, was instrumental in the passage of Kendra’s Law, which has proven extraordinarily successful since it went into effect November 1999.

Recognize that laws change in reaction to tragedy

Laws do not change to provide more humane care for people with brain disorders. Laws change when the public becomes concerned about their own safety. While it is true that assisted treatment helps consumers, it is also true that it keeps the public safer. An act of violence, however horrible, is an opportunity to jump start reform. Nobody is saying this is right, but it is true. So you have to be prepared to use tragedies to educate.

Prepare materials ahead of time

Fact sheets and newspaper clippings let you put together professional looking kits to quickly send to the media, legislators and others. One of our fact sheets listed states that had the law we were trying to enact. Another debunked false information spread by others. We also had fact sheets on schizophrenia, lack of insight, violence, efficacy of treatment and others. We also used newspaper clippings, including “Uncivil Liberties,” and editorials and op-eds that supported our cause.

Work through criminal justice types rather than the Office of Mental Health

The strongest governmental supporters are likely to be those charged with criminal justice, rather than mental health care. They understand the consequences of the failure to provide care and how that affects quality of life issues and crime.

Get victims, perpetrators, and their families to speak out

Because laws change in reaction to violence, it is useful to have the perpetrators and victims of crime on your side. The New York bill would not have passed without the Webdale, Stevens, and Rivera families, all of whom were affected by acts of violence by people with mental illnesses.

Work the media one-on-one

Spend a lot of time and energy with reporters and editorial writers. When a tragedy occurs instantly reach out to reporters so their reporting includes how this law could prevent tragedy. A story is likely to play out over several days, so don’t think you missed the boat if you weren’t in the first story.

Make a list of “supporting organizations”

Do not form a committee or a working coalition. It will suck up time better spent talking to legislators and the media, who can effect the change you want. But do create a list of “Supporting Organizations” that makes others realize the widespread support reform has and how mainstream it is. In addition to your NAMI affiliate, your list might include bar, community, sheriff, police, nurse, health care, and other associations.

Make sure to recognize all the local NAMIs that support you, not just the state and national NAMI.

Marginalize the opposition

It is important to communicate that there is very little opposition to reform. Continue to remind the public how small and fringe the opposition is and how large and mainstream the support is.

Capitalize on NAMI members and other supporters

Local NAMI organizations and individuals were willing and enthusiastic supporters in New York. Make sure to recognize all the local NAMIs that support you, not just the state and national NAMI. Use local members to do the grassroots work, like letter writing.

Keep in touch via e-mail, but don’t forget “snail” mail

E-mail is a great way to keep people informed and involved. Start an e-mail list of reformers. But remember those who don’t have e-mail, either by using fax or regular (“snail”) mail. Faxes are efficient.

Try writing op-eds and contacting editors

TAC can help with this. Contact editorial writers and ask for their support. In New York, we got Kendra’s Law endorsed by the conservative *Daily News* and *New York Post* and the liberal *New York Times* and *Newsday*. [Editor’s note: See sample opeds and editorials online at www.psychlaws.org, in the “General Resources” section.]

A GRIEVING MOTHER:
Passion, persistance, and pals helped turn tragedy into activism

by Pat Webdale

Kendra's Law is named in memory of Kendra Webdale. In January 1999, the 32-year-old Buffalo native was killed after being pushed into the path of a New York City subway train by Andrew Goldstein, a man with severe mental illness who had a history of noncompliance with treatment. Kendra's family was instrumental in the passage of this law, advocating tirelessly for reform. Here, Pat Webdale offers some things she learned throughout the difficult battle for passage.

My daughter Kendra was pushed off of a subway platform into the path of an oncoming train on January 3, 1999. Her assailant was diagnosed with schizophrenia and was not taking his medicine. I vowed to do something to help prevent future tragedies.

Kendra's death was high profile, one of 11 million subway riders trying to make her way in a big city. Would a law named in her honor bring peace to another family?

Know your subject

We hooked up with the experts, the people at the Treatment Advocacy Center and NAMI. My daughters purchased *Out of the Shadows* and *Surviving Schizophrenia* by TAC president Dr. E. Fuller Torrey. We read about the loss of a family member to mental illness and about the system; navigating, negotiating, the throwing up of hands in total disillusionment at its inadequacies. The mentally ill had to live on the street, be thrown in jail or become dangerous to self or others in order to receive treatment.

Watch for opportunities

Only five days after Kendra died, I wrote a letter to Eliot Spitzer, the Attorney General of New York State, challenging procedures in which his office would no longer review OMH discharges. New York was under fire after Judith Scanlon, a psychiatric nurse and intensive case manager, had been murdered by her client while making an unaccompanied home visit. My daughter Krista sent a letter to Governor Pataki, saying, in part: "When Mrs. Scanlon started her psychiatric nursing career, the Buffalo Psyche Center had 3,000 beds and today there are 260 beds. We are releasing far too many patients into unsupervised environments where they are unable to function."

KENDRA'S LAW SAVES LIVES AND MONEY

In a little less than three years after implementation, 2,433 people received assisted outpatient treatment (AOT) orders. After six months in AOT, the incidence of hospitalization, homelessness, arrest, and incarceration had all declined significantly from their pre-AOT levels. In fact, of those in the program:

- 77% fewer experienced hospitalization;
- 85% fewer experienced homelessness;
- 83% fewer were arrested; and
- 85% fewer were incarcerated.

There were also significant reductions in harmful behaviors among participants, such as harm to self (45% reduction) and harm to others (44% reduction).

New York's State Office of Mental Health, *An Interim Report on the Status of Assisted Outpatient Treatment,* Jan. 1, 2003.

The attorney general was about to introduce an assisted outpatient treatment bill to help people with serious brain disorders to obtain treatment. He suggested the law be named to honor Kendra.

Ask questions

Suzanne, a mental health professional, questioned the bill – would it work? She opposed putting Kendra's name on a law that would have no teeth. In response, the attorney general allowed her to work closely with his office as the bill was drafted.

Be persistent

We traveled to Albany seven times and met with the attorney general three times in Buffalo. We endured traffic jams, getting lost, bad meals, late nights and unkempt hotels.

We called and wrote personal letters to the senate, the assembly and the governor almost daily. I spoke to the NAMI board of New York, to ask for its support for assisted outpatient treatment.

Be creative

We approached the matter with a bipartisan attitude. Copyboy donated 1,000 business cards with Kendra's picture on it to be distributed statewide – the cards read "Pass Kendra's Law" with phone numbers of strategic legislators.

Be passionate – and compassionate

Kendra is grieved everyday and we understand that the mentally ill are also grieved and lost to their families. Other passionate people were definitely a huge help – for instance, all the people who made phone calls, who knows how many of them had a mentally ill family member?

Since it was passed, Kendra's Law has had a proven track record and has changed the system in substantial ways in New York. We are confident that our passionate crusade is saving and improving lives.

A COURT PERSPECTIVE:
How we changed our law in West Virginia

by Tom Rodd, Senior Law Clerk, West Virginia Supreme Court of Appeals

In 1999, the West Virginia Supreme Court of Appeals formed a Mental Hygiene Reform Commission to look at West Virginia's laws and procedures governing involuntary hospitalization. A number of the Commission's recommended improvements were contained in Senate Bill 193, which went into effect July 2001. Tom Rodd and his boss, Supreme Court Justice Larry Starcher, continue to push the legislature for a law like New York's Kendra's Law, a law that would, as Tom said in a recent newspaper editorial, "explicitly authorize some of our state's mental-hygiene commissioners, using full due process, to require people to take medications, especially when their repeated noncompliance with prescribed medication has led to repeated involuntary hospitalizations based on their dangerousness to self or others." Tom highlights some things they have learned so far.

In West Virginia, the State Supreme Court of Appeals administers a system of "mental hygiene" commissioners who must hold a hearing to authorize all involuntary hospitalizations for treatment of mental illness and addiction. In 1999, the court convened a Mental Hygiene Reform Commission to consider improvements to our system. We held hearings statewide and brought together stakeholders for a series of meetings and discussions. The Commission issued a report, which is on the web at http://www.state.wv.us/wvsca/mentalhyg/finalmh.pdf.

We found it relatively easy to get consensus on the need to clarify the legal standard used for commitment decisions to include "need for treatment," and also to improve flexibility in the system – and with this consensus, our statutes were successfully modified in this regard. There was also support in the Commission process for removing the need to always have a hearing, and for authorizing court orders that explicitly require people to get outpatient treatment. But there was also opposition to these proposals, so they did not succeed legislatively. We did achieve consensus and modify the law to let court officers approve "voluntary treatment agreements," and to allow release from a hospital upon the condition of complying with treatment. These options, if utilized, can help more people get effective outpatient treatment, as well as ease the process of hospitalization when necessary.

The Commission process was challenging and engaging. The enhanced statewide understanding of the issues, and the statutory changes that flowed from the process, were real accomplishments. But in order to get effective, least-restrictive and community-based treatment to people who need it, we clearly need more changes in our law. Several factors combine to impede the progress of change in this area. State medical authorities fear that streamlining procedures, combined with the "need for treatment" standard and the supervision and monitoring inherent in orders relating to outpatient treatment, will add burdens to a state mental illness treatment system that is already financially overloaded. Also, those who oppose all forms and degrees of compulsion in treating mental illness tend to oppose change, as do those who are accustomed to and/or have vested interests in current structures and procedures.

The deliberate, "let's reason together" consensus approach of the Commission process may have reached its limits of effectiveness. Further change may be sparked by tragedies. Just last month, here in Charleston (our state capitol), a man who has a chronic mental illness and problems taking prescribed medicine killed his mother/caretaker, a 58-year-old librarian. Hopefully recognition of the flaws in the system — that contribute to this sort of incident – will lead to the additional changes in the law that are necessary, and in the long run, inevitable

Want to get involved in your state? The Treatment Advocacy Center's web site is a good place to start. Look up your current state law, then mobilize to change it – or make sure it is used correctly.

- **Does your state allow assisted outpatient treatment, also known as court-ordered outpatient treatment? All but nine states do: Connecticut, Florida, Maine, Maryland, Massachusetts, Nevada, New Jersey, New Mexico, and Tennessee.**
- **Does your state require someone to be dangerous before they can be court-ordered to treatment? About half of states require someone to be dangerous, which limits help for people until they are in crisis.**
- **Does your state use the law it has?**
- **Is there activity already happening in your state?**

Visit us online at: http://www.psychlaws.org/GeneralResources/advocates.htm to find out and get involved.

A NATIONAL LEADER AND ADVOCATE:

Tenacity prevails: Never give up

by Carla Jacobs

California law kept Carla Jacobs and her husband, Brian, from getting mental health intervention for Brian's sister, despite the fact that she did not believe she was ill. The struggle came to a terrible end when Brian's mother was killed by her delusional daughter. Carla's grief led her to become one of the nation's most effective advocates for changing treatment laws.

For four years, Carla supported the efforts of California Assemblymember Helen Thomson, a former psychiatric nurse, who introduced a string of reform measures that culminated in the passage of Laura's Law (AB 1421).

Don't give up, don't get discouraged

Helen Thomson introduced a string of reform bills over three years. At first, it was discouraging to have to keep coming back, but then we discovered that with each subsequent bill, people were more informed about mental illnesses, more understanding of the need to help people who lack insight, more aware of how this bill would not compromise civil rights but would, in fact, protect them. When AB 1800 – our first attempt – did not become law, we realized that the bill had made a tremendous impact not only as an education tool but on the advocates who supported it – we learned that we could galvanize the media, legislators, and public officials behind common-sense proposals.

Today, with Laura's Law on the books, the battle continues – this time to get counties to implement it and people to use it.

Rejoice in every victory but never believe you have won

The second time we introduced a bill in California, the legislature passed AB 1424, requiring courts making commitment determinations to consider past psychiatric history and family input. Unbelievably, most courts had previously refused to examine such evidence. This was a tremendous improvement on current law and helped many people – but it was far short of our ultimate goal of complete reform. We celebrated, then woke up the next morning to try again, knowing the law was a little better. Today, with Laura's Law on the books, the battle continues – this time to get counties to implement it and people to use it.

Build a list of supporters

Registering support for a bill requires little effort. A sheet of letterhead, a stamped envelope, and a few sentences including the bill number are all it takes. Yet a supporter list can be an exceptional asset for a proposed measure. We ended up with almost 80 organizations supporting our reform effort (see an example list at www.psychlaws.org/StateActivity/California/factsheet8.htm).

Pay attention to the calendar

In the course of our efforts in California, we encountered many situations where a hearing time was changed or location moved, or a hearing delayed because of some technical glitch – in one instance, the Senate actually left a week early for its summer recess, leaving our bill high and dry. These can seem like logistical points only, but delays offer additional opportunities to lobby, write letters, make calls, or add supporters. And missing information on a hearing time or location changing might mean witnesses go to the wrong place and their testimony is never heard. So make sure someone is watching not only the clock, but also the calendar.

Write thank-you notes

It is critical to write letters to legislators sharing personal stories and urging support. (In our final push, more than 1,000 individual registered their support for AB 1421, over three times those opposed.) But there is still more writing to do.

After each meeting, hearing, phone call, or accidental conversation in the hallway, send a thank-you note. Thank the people who support you and give them more reason to do so. Thank the people who are opposed for caring enough to listen, then explain why they should change their mind. Don't be disparaging of people who are against reform, just assume that they need more information. Legislators need to know how closely their constituents follow these reform measures. Remember the bill you are supporting today will not be the last one vital to people with mental illness.

Los Angeles was the first county to implement Laura's Law, new legislation that allows court-ordered, intensive outpatient treatment for people with severe mental illnesses who refuse medication because their illness impairs their ability to make rational decisions. If successful - which we are positive it will be - more assisted outpatient treatment programs in L.A., and hopefully other counties, will follow. Watch for updates at www.psychlaws.org.

Five years with hope: Thirty years of despair

by Treatment Advocacy Center Executive Director Mary T. Zdanowicz

A quarter century after a federal court in Wisconsin overturned her civil commitment to outpatient treatment, the *Milwaukee Journal Sentinel* reported that Alberta Lessard "is not happy with the legacy of her lawsuit. She thinks life has gotten worse, not better, for the mentally ill since her lawsuit began in October 1971." In the five years that the Treatment Advocacy Center has been in existence, we have seen indications that the courts have a much better understanding of the realities of severe mental illnesses, but we also know that our work is far from done.

We have come a long way since *Lessard v. Schmidt*[1], the 1972 case that introduced the concept of imminent danger as a prerequisite to assisted treatment. Each year, we have had encouraging indications from court decisions.

> **"A jail is a poor mental hospital," says Bibb County Probate Judge Bill Self, who presides over involuntary commitment hearings for people with mental illness.**
>
> – "Making mental illness a crime: For more Georgians, disorders mean time in jail, not treatment centers," *The Macon Telegraph*, Jan. 27, 2002

1998 Utah court: Treatment is not punishment, intervention before danger is humane

While the Lessard court interpreted danger strictly as an "extreme likelihood that if the person is not confined he will do immediate harm to himself or others,"[2] twenty-six years later, a federal court in Utah issued an important decision favoring needs-based treatment for those suffering from severe mental illnesses in *Jurasek v. Utah State Hospital*[3]. The court ruled that a state psychiatric hospital could order involuntarily treatment for a mentally ill patient who was "gravely disabled" and incompetent to make medical decisions. "Gravely disabled" as defined in the Utah policy includes a person who suffers from a mental disorder who "manifests, or will manifest, severe deterioration in routine function evidenced by repeated and escalating loss of cognitive or volitional control over his or her actions and is not receiving such care as is essential for his or her health or safety"[4]. The court found that this definition incorporates the concept of "danger to self" and therefore is consistent with prior U.S. Supreme Court decisions authorizing administration of medication over objection for individuals who "pose a likelihood of serious harm" to themselves or others.[5] The Utah court also clarified that an individual who "lacked the ability to engage in a rational decision making process regarding the acceptance of mental treatment" was legally incompetent to make medical decisions on his own behalf.[6] The Utah decision supports early treatment intervention for an individual who does not recognize that they need treatment and whose condition will deteriorate to a harmful state without treatment.

Perhaps one of the most significant and encouraging aspects of the decision is that the court explicitly states that it is based on "the fact that treatment with psychotropic drugs is not punishment."[7] This may be an indication that courts are beginning to recognize that it is more humane to alleviate devastating symptoms of these illnesses by administering treatment than to withhold medication from a person who is refusing because they lack insight into their illness and therefore lack the capacity to make an informed decision.

1999 U.S. Supreme Court: Warns against massive deinstitutionalization, lack of treatment leads to peril

In *Olmstead v. L.C. ex rel. Zimring*[8], the U.S. Supreme Court decided a case concerning a state's obligation to provide community mental health treatment to people institutionalized with severe mental illnesses. Although the Court imposed certain qualifiers on a state's responsibility in this regard, it also made clear the decision was not a call for massive deinstitutionalization. "[T]he ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk."[9] In his concurring opinion in Olmstead, Justice Kennedy quoted

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[1] *Lessard v. Schmidt*, 349 F.Supp. 1078, (E.D.Wis.1972), vacated and remanded on other grounds, 421 U.S. 957, 95 S.Ct. 1943, 44 L.Ed.2d 445 (1975), reinstated 413 F.Supp. 1318 (E.D.Wis.1976)

[2] *Lesard*, 349 F.Supp. at 1093.

[3] *Jurasek v. Utah State Hospital*, 158 F. 3d 506 (10th Cir. 1998).

[4] Id. at 511.

[5] Id. at 512.

[6] Id. at 513.

[7] Id. at 511.

[8] *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999).

[9] Id. at 604.

TAC president Dr. E. Fuller Torrey:

> For a substantial minority … deinstitutionalization has been a psychiatric Titanic. Their lives are virtually devoid of 'dignity' or 'integrity of body, mind and spirit.' 'Self-determination' often means merely that the person has a choice of soup kitchens. The 'least restrictive setting' frequently turns out to be a cardboard box, a jail cell, or a terror-filled existence plagued by both real and imaginary enemies.[10]

"As a criminal court judge, I have observed that the majority of mentally ill people who appear in my court have stopped taking their medication. … I could stop the revolving courtroom door for many of these individuals from the bench if I could order them to take the medication they need when they leave my court."

– Florida Judge Steven Leifman, *Washington Post*, Aug. 16, 2001

Justice Kennedy, in his own words, displayed how deeply he understands the dilemma of untreated mental illness:

> It must be remembered that for the person with severe mental illness who has no treatment, the most dreaded of confinements can be the imprisonment inflicted by his own mind, which shuts reality out and subjects him to the torment of voices and images beyond our own powers to describe. …
>
> It is a common phenomenon that a patient functions well with medication, yet, because of the mental illness itself, lacks the discipline or capacity to follow the regime the medication requires.[11]

This landmark case was especially extraordinary because this U.S. Supreme Court justice recognized that severe mental illnesses are themselves confining.

2000 New York: Kendra's Law is constitutional

The judicial response to Kendra's Law in New York has provided some of the most encouraging evidence that the judiciary has a profound understanding of the realities of untreated mental illnesses. Kendra's Law was enacted in 1999 after a man with untreated schizophrenia pushed 32-year-old Kendra Webdale to her death in front of a subway train. It allows court-ordered outpatient treatment for individuals with a history of treatment noncompliance and revolving door syndrome.

"This was a vicious act, but I understand it was a chemical imbalance. Putting him in jail would be like punishing him for a disease."

– Judge Eugene Lucci, speaking of a man with schizophrenia who tried to kill his family, from "Judge grants family's wish to spare son from prison," *Cleveland Plain Dealer*, June 28, 2002

The court upheld Kendra's Law in the first of several unsuccessful challenges in the case *In re Urcuyo*[12], saying:

> Kendra's Law is a means by which patients who have such a history can be discharged to the community with the supervision and assistance they need to avoid decompensation and rehospitalization.…[13]

Kendra's Law provides the means by which society does not have to sit idly by and watch the continuous cycle of decompensation, dangerousness and hospitalization. Moreover, Kendra's Law is narrowly tailored to achieve these goals within the framework of the involuntary and emergency commitment procedures of the Mental Hygiene Law.[14]

2001 New York: Kendra's law protects civil liberties

Another trial court reached similar conclusions in another unsuccessful challenge to Kendra's Law in *In re Martin*[15]. The judge in the Martin case noted that:

> Kendra's Law is a response by the Legislature to a tragic situation which had its origins in a serious void in New York's system of caring for the mentally ill. That void arose from the fact that certain patients, who no longer posed a danger to themselves or others while in hospital and accepting medication and treatment, stopped taking their medication upon release. Thereupon, these patients would once again constitute a danger to themselves or others, sometimes with tragic results.

2002 Wisconsin: Courts can and should intervene when recidivists lack insight and need treatment

Perhaps the most far-reaching decision came in July 2002 from the Wisconsin Supreme Court, the state where the *Lessard* case originated thirty years earlier. *In re Dennis H.*[16] involved a challenge to Wisconsin's so-called "fifth standard" for assisted treatment, which is among the most progressive, need-based treatment standard in the country. The fifth standard allows a person to be placed in treatment

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[10] Id. at 609 (Kennedy, J., concurring in the judgment).

[11] Id.

[12] *In re Urcuyo*, 714 N.Y.S.2d 862 (N.Y. Sup. Ct. 2000),

[13] *In re Urcuyo*, 714 N.Y.S.2d 862, 872 (N.Y. Sup. Ct. 2000).

[14] Id. at 873.

[15] *In re Martin*, N.Y. L.J., Jan 9, 2001, at 25 (N.Y. Sup. Ct., 2001).

[16] *In re Dennis H.*, 647 N.W.2d 851 (2002).

when if left untreated, he or she will “lack services necessary for his or her health or safety and suffer severe mental, emotional or physical harm that will result in the loss of the individual’s ability to function independently in the community or the loss of cognitive or volitional control over his or her thoughts or actions.”[17]

> **“I feel our mental health system is completely inadequate ... They dropped the ball. What’s amazing is how many times mentally ill people are in the hospital and released. It’s incredibly frustrating.”**
>
> **– North Carolina Judge William Wood Jr, pronouncing sentence on a man with severe mental illness who shot two coworkers, *News & Record*, Dec. 5, 2001**

The court not only unanimously upheld the standard, it demonstrated just how much courts have learned in the 30 years since the decision Alberta Lessard laments today. The court wrote:

> Mentally ill persons who meet the fifth standard’s definition are clearly dangerous to themselves because their incapacity to make informed medication or treatment decisions makes them more vulnerable to severely harmful deterioration than those who are competent to make such decisions. The state has a strong interest in providing care and treatment before that incapacity results in a loss of ability to function.[18]
>
> The fifth standard’s focus is on dangerousness to self—dangerousness of a particularly insidious nature because it is chronic and cyclical (measured by treatment history and recent acts or omissions), and brought on by mental illness that produces an incapacity to make medication or treatment decisions as well as a substantial probability of an incapacity to care for oneself.[19]
>
> Moreover, by requiring dangerousness to be evidenced by a person’s treatment history along with his or her recent acts or omissions, the fifth standard focuses on those who have been in treatment before and yet remain at risk of severe harm, i.e., those who are chronically mentally ill and drop out of therapy or discontinue medication, giving rise to a substantial probability of a deterioration in condition to the point of inability to function independently or control thoughts or actions.[20]
>
> The fifth standard applies to mentally ill persons whose mental illness renders them incapable of making informed medication decisions and makes it substantially probable that, without treatment, disability or deterioration will result, bringing on a loss of ability to provide self-care or control thoughts or actions. It allows the state to intervene with care and treatment before the deterioration reaches an acute stage, thereby preventing the otherwise substantially probable and harmful loss of ability to function independently or loss of cognitive or volitional control. There is a rational basis for distinguishing between a mentally ill person who retains the capacity to make an informed decision about medication or treatment and one who lacks such capacity. The latter is helpless, by virtue of an inability to choose medication or treatment, to avoid the harm associated with the deteriorating condition.[21]

2003 Oregon: Education of the judiciary must continue

As if to remind us that we must remain vigilant, in 2003 the Oregon Court of Appeals overturned a commitment order for a woman with untreated bipolar disorder who rode her bicycle naked in near freezing weather. Terri Webb’s attorney’s argued *In Re Webb*[22], that she rode naked to educate people about legalizing public nudity, that cold weather did not bother her, and that she was not afraid of being assaulted while riding naked. Because she had never been assaulted while riding naked and it was not clear whether she rode long enough in the cold to suffer exposure, the appeals court did not agree with the trial court that she put herself in danger[23]. The danger was not real or immediate enough for the court. If some day Ms. Webb finally gets the treatment she needs, she may discover that she feels the same about her appeal as Alberta Lessard. This case imperils the thousands who will not get the treatment they so obviously need until informed courts are more prevalent.

There is evidence, in these cases and others, that the trend in courts is toward humane understanding of the effects of a severe mental illness not only on the general community, but most importantly, on the people who are ill.

> **“[W]e are dealing with these cases one way or another. That is, if we do not handle the cases on the civil docket for court-ordered treatment, we will have to deal with them on the criminal docket when crimes are committed, often as a result of the untreated symptoms of their illness.”**
>
> **– Wisconsin Circuit Court judge Ralph M. Ramirez**

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[17] Wis. Stat. § 51.20(1)(a)2.e (1995).

[18] In re Dennis H., 647 N.W.2d at 862.

[19] Id. at 860.

[20] Id. at 863.

[21] Id. at 861-2.

[22] In Re Webb, 63 P.3d 1258 (Or. Ct. App. 2003).

[23] Id. at 1261.

Research

Studies bolster efforts to educate and legislate

Studies and data from states using assisted outpatient treatment (AOT) prove that AOT is effective in reducing the duration and incidents of hospitalization, homelessness, arrests and incarcerations, victimization, and violent episodes. AOT also increases treatment compliance and promotes long-term voluntary compliance.

AOT reduces hospitalization

A report by the New York Office of Mental Health on the first three years of implementation of Kendra's Law indicated that of those participating, 77 percent fewer experienced hospitalization (87% versus 20%). In a North Carolina study, long-term AOT reduced hospital admissions by 57 percent and length of hospital stay by 20 days compared to individuals without court-ordered treatment. The results were even more dramatic for individuals with schizophrenia and other psychotic disorders for whom long-term AOT reduced hospital admissions by 72 percent and length of hospital stay by 28 days compared to individuals without court-ordered treatment.

> **“AOT has increased accountability at all levels regarding delivery of services to individuals who have high needs and who are at high risk to themselves or others.”**
>
> **- New York's State Office of Mental Health, *An Interim Report on the Status of Assisted Outpatient Treatment*, Jan. 1, 2003.**

AOT reduces homelessness

In New York, the number of people experiencing homelessness was reduced by 85 percent, from 21 percent of participants prior to the onset of a court order, to 3 percent after being in the program.

AOT reduces arrests

Arrests for those Kendra’s Law’s participants were reduced by 83 percent, plummeting from 30 percent prior to the onset of a court order to only 5 percent after participating in the program. A North Carolina study found that for individuals who had a history of multiple hospital admissions combined with arrests and/or violence in the prior year, long-term assisted outpatient treatment reduced the risk of arrest by 74 percent. The predicted risk of being arrested for individuals in long-term AOT was 12 percent, compared with 47 percent for those who had no AOT.

AOT reduces violence

For those in the first three years of Kendra’s Law in New York , data indicate that incidents of harm to others was reduced by 44 percent. The North Carolina study found that long-term AOT combined with routine outpatient services (three or more outpatient visits per month) was significantly more effective in reducing violence than routine outpatient care without long-term AOT. Long-term AOT combined with routine outpatient services reduced the predicted probability of violence by 50 percent.

AOT reduces victimization

A 2002 North Carolina study demonstrated that individuals with severe psychiatric illnesses who were not on outpatient commitment "were almost twice as likely to be victimized as were outpatient commitment subjects." 24 percent of those on outpatient commitment were victimized, compared with 42 percent of those not on outpatient commitment. The authors noted "risk of victimization decreased with increased duration of outpatient commitment,” and suggest that "outpatient commitment reduces criminal victimization through improving treatment adherence, decreasing substance abuse, and diminishing violent incidents" that may evoke retaliation.

AOT improves treatment compliance

In New York, poor medication adherance dropped significantly, from 67 percent to 22 percent, after six months of assisted outpatient treatment. In North Carolina, only 30 percent of patients on AOT orders refused medication during a six-month period compared to 66 percent of patients not on AOT orders. In Ohio, AOT increased patients' compliance with outpatient psychiatric appointments from 5.7 to 13.0 per year; it also increased attendance at day treatment sessions from 23 to 60 per year.

AOT also promotes long-term voluntary treatment compliance. In Arizona, among patients in assisted outpatient treatment, "71 percent ... voluntarily maintained treatment contacts six months after their orders expired" compared with "almost no patients" who were not court-ordered to outpatient treatment. And in Iowa "it appears as though outpatient commitment promotes treatment compliance in about 80 percent of patients while they are on outpatient commitment. After commitment is terminated, about three-quarters of that group remained in treatment on a voluntary basis."

Memorials and Tributes

Our deepest appreciation to the people and organizations who sent in memorials and tributes since our last issue of *Catalyst*. We are grateful that you chose to support the Treatment Advocacy Center's mission in memory or in honor of someone very special to you. Your generous contributions allow us to continue our mission.

– The board and staff of the Treatment Advocacy Center

Carl and Allene, Piazza, Jamestown, NY	In honor of our sickest people with mental illness
Mary Sesti, Monterey Park, CA	In honor of Lisa Sesti, daughter
June and John Husted Travis, Rancho Palos Verdes, CA	In memory of Todd Ellery Husted
NAMI North Carolina, Raleigh, NC	In honor of Dr. E. Fuller Torrey
Traian and Camilla Moga, Seabrook, TX	In gratitude for all that you do
Melinda Crary, Dove Canyon, CA	In honor of my son, Jordan Molina
Gale Barshop, Alexandria, VA	In memory of Lynn Arden
John and Yolanda Wilson, Lakewood, CA	In honor of LAC DMH
Isabel Ehrenreich, Flintridge, CA	In memory of Mark S. Ehrenreich
Florence Keenan, Chevy Chase, MD	In memory of James McAlear
Tex and Jane Moser, Springfield, MA	In honor of David Lee Moser
Hollis and Marilyn Booth, Inverness, FL	In honor of Dr. Mercedes A. Brito
Eugene and Linda Murphy, Palm Coast, FL	In honor of Jeff Richmond (son)
Eileen Rorick, Orange Springs, FL	In honor of Michael Rorick
Cynthia Montano, Old Bridge, NJ	In memory of Joseph R. Montano,
Louis and Margarit Iparraguirre, Indian Harbour Beach, FL	In memory of Sharon Harding 1964–2003
Robert and Catherine Popek, Clifton, NJ	In honor of Dr. E. Fuller Torrey
Donald and Ann Bonevich, Kalamazoo, MI	In honor of NAMI of Kalamazoo
Elaine Mickman, Narberth, PA	In honor of Richard
Katie Vath, Lake Worth, FL	In honor of Tim Pedon
Linda Gregory, Enterprise, FL	In memory of Deputy Eugene Gregory
Don Daves, Duluth, GA	In memory of Susan Daves
William and Marianne Kernan, Pinehurst, NC	In honor of Keith Kernan
Carl and Tirza Rivera Cira, Pinecrest, FL	In honor of Rose Cira
Harding and Marion Sortevik, Amherst, NH	In honor of son, Paul
Keith Mundt, Riverside, CA	In memory of Winifred Mundt
Marcia Barnes, Ocala, FL	In thanksgiving
Pat Williams, Davis, CA	In honor of Carla and Brian Jacobs, CTAC
John & Janice DeLoof, Fullerton, CA	In memory of Brad DeLoof
Caren Staley, Federal Way, WA	In memory of Domenico Vomenici
Merry Kelley, Hiawatha, IA	In memory of my daughter, Bonnie Picard
Frank and Stephanie Dillbeck, Twentynine Palms, CA	In memory of Sharra Hurd
Mary Zdanowicz, Arlington, VA	In honor of Lorraine Gaulke

Catalyst

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Thanks to generous support from people like you, the Treatment Advocacy Center has accomplished much in its five years of existence. As we launch our next five years, we are already involved in a number of campaigns across the country to update treatment laws. This requires a great deal of work for our small staff, and we need your help if we are to continue our successful work against well-financed opponents. If you have supported us in the past, we ask you to consider giving again now. If you have never been able to support us in the past, we would very much appreciate your support now.

Remember that the Treatment Advocacy Center does not accept funding from pharmaceutical companies or entities involved in the sale, marketing or distribution of such products. So your help is really important.

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