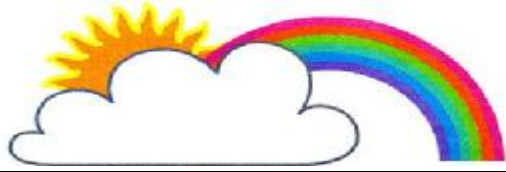


NEVER say NEVER



*In the midst of the seemingly endless storm,
look to the promise of the rainbow -
the rain shall not prevail!*

Fall 2007

OCD: The Parents' Perspective

By Jennifer Shanburn
and Robert and Barbara Polsgrove

In a recent issue of this newsletter, I interviewed my husband about OCD and its effects in our life and relationship. I also thought it would be enlightening and helpful to sit down with my parents, Rob and Barb Polsgrove, and interview them about the effects of OCD on our lives in the past and present. Our hope is that other parents who have children with OCD will feel comfort in knowing there are others who have gone through similar experiences and also that they can gain some helpful insight into these difficult experiences.

Tell me about when you first noticed me having symptoms that you later found out were OCD and what your reaction/feelings were?

When you were around 3 ½ years old, you all of a sudden wouldn't eat because you thought the food and eating utensils were dirty. You stopped eating for about 2 days. It was very frightening and bewildering to us. In retrospect, we think you may have been sick at the time, possibly with strep throat, which as we know now can be the trigger for genetically predisposed OCD. Thankfully that first episode passed fairly quickly. Subsequently throughout your later childhood we noticed other symptoms as well, not knowing the cause.

How did you finally find out what was happening and what was that like for you?

I [Barb] read The Boy Who Couldn't Stop Washing by Judith Rapoport when you were 13 years old and in another major episode and realized OCD could be what you had. So we took you to the University of Michigan's anxiety disorders clinic where you received the diagnosis of OCD. It was a great relief to be able to put a name to it. Some of the other possible explanations for your behavior were far worse. We were finally able to know what sort of therapy to find for you and we were educated about OCD. We worked together with you in cognitive-behavior therapy (CBT) to help you manage the disorder.

What would have been helpful for you as a parent of a young child with OCD?

Getting an earlier diagnosis would have been helpful. Finding a therapist sooner who knew about OCD and how to treat it and who would work closely with us. Therapy for us as parents would have been helpful, to understand our own feelings of guilt and also to help with the overwhelming sense of how to deal with this within our family. The child is getting CBT but parents, at least initially, should be involved in therapy to be able to talk out their own feelings about it.

What would you like to say to parents who have children or teens with OCD? Any words of wisdom?

It isn't who your child is – don't ever let it be who your child is. The disease doesn't define who your child is. And never give up. OCD is manageable. You just stick together in the tough times and the

THE OCD FOUNDATION OF MICHIGAN

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* Thanks to Mark Fromm, president of Business Growth Today, Inc., for hosting our website.

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NEVER say NEVER

is the quarterly newsletter of the OCD FOUNDATION OF MICHIGAN,
a non-profit organization.

Please note that the information in this newsletter is not intended to provide treatment for OCD or its associated spectrum disorders. Appropriate treatment and advice should be obtained directly from a qualified and experienced doctor and/or mental health professional. The opinions expressed are those of the individual authors.

To submit articles or letters, write or e-mail the OCDFM at the above addresses.

LIST OF SELF-HELP GROUPS

ANN ARBOR:

Currently not meeting
Call Mary Jo at (734) 883-4038

DEARBORN:

2nd Thursday, 7-9 PM
First United Methodist Church
Garrison and Mason Streets
Call (313) 438-3293

FARMINGTON HILLS:

1st and 3rd Sundays, 1-4 PM
Trichotillomania Support Group
Botsford Hospital
Administration & Education Center,
Classroom C
28050 Grand River Ave. (North of 8 Mile)
Call Bobbie at (734) 522-8907

GRAND RAPIDS:

Old Firehouse #6
312 Grandville SE
Call the Anxiety Resource Center
(616) 356-1614

www.anxietyresourcecenter.org

Anxiety (all forms)

Meets every Wednesday, 7 to 9 p.m.
Open to individuals who have any kind of anxiety problem as well as their friends and family members.

Adults Obsessive-Compulsive Disorders

2nd and 4th Tuesdays, 7 to 9 p.m.
Open to any adults who have or think they may have Obsessive-Compulsive Disorder. Friends and family members welcome.

Young Adults OCD

1st Monday, 5:30 to 6:30 p.m.
A monthly support group for young adults, aged 16 to 21, who have or think they may have Obsessive-Compulsive Disorder. Friends and family members welcome.

Body Focused Repetitive Behaviors

1st Tuesday, 7 to 9 p.m.
A monthly support group for adults who have Compulsive Hair Pulling, Skin Picking and Nail Biting problems. Open to friends and family members.

Compulsive Hoarding

3rd Tuesday, 7 to 9 p.m.
A monthly support group for people who have trouble with compulsive hoarding. The group is open to friends and family members.

Other Kids Like Me

1st Tuesday, 4:30 to 5:30 p.m.
A monthly support group for children, aged 7 to 15, with compulsive habits that seriously interfere with their lives including Obsessive-Compulsive Disorder, Compulsive Hair Pulling, Skin Picking, Nail Biting, Obsessions Around Appearance or Health and Tic Disorders.

HOLLAND:

Call Geraldine at (616) 335-3503 or
Tony at (616) 396-5089

LANSING:

1st Thursday, 7:30-9 PM
Delta Presbyterian Church
6100 W. Michigan
Call Jon at (517) 485-6653

ROYAL OAK:

1st and 3rd Tuesdays, 7-9 PM
St. John's Episcopal Church
115 S. Woodward at 11 Mile
Call Terry at (586) 790-8867

SPRING LAKE / MUSKEGON / GRAND HAVEN:

1st and 3rd Mondays, 7-9 PM
Spring Lake Wesleyan Church, Classroom E-111
Call Pam at (231) 744-3585

AKRON, OH

Parents of Kids with OCD
3rd Monday, 7 PM
Outpatient Pediatric Psychiatry Dept.
Akron Children's Hospital, 300 Locust Street
Suite 280 in Conf. Room
Call Susan at (330) 499-0373
To receive free e-newsletter,
Contact Marie at ooocccddkids@yahoo.com

AKRON/CANTON, OH

OCD/Scrupulosity
2nd and 4th Tuesdays, 7 - 8:30 PM
Queen of Heaven Parish, (In the Bride's Room)
1800 Steese Road, Green, OH
Call Susan at (330) 499-0373

good times. Encourage your child and don't enable him/her. It is frightening. It breaks your heart for your child to have to suffer. Something that's hard about it is that it's a disease but other people don't often see it, so they don't understand. And they're afraid of it, because it seems weird or strange, just like they're afraid of any mental illness. So they just don't ever want to talk about it. With other diseases, they might ask about how your child is doing, but not with OCD.

As I have moved into being your adult child who has OCD, have there been any particular challenges or triumphs?

Challenges are that we have to be more hands-off in that you don't involve us as much. When we don't hear about it, we assume that you're doing better but we don't know. You are definitely managing it better. You have gained more control over it. You haven't had a major episode of it for so long, which makes us

feel so happy and proud. We're very proud because it's so hard. We respect your tenaciousness of not letting it overcome you.

What do you wish your friends/family and also the general public knew about OCD and having a child with OCD?

When you were younger, we wish we could share more openly about it because it still has stigma. But any mental illness has a stigma. You don't want people to think that there's something wrong with you as parents if there's something wrong with your child. We wish people wouldn't be so quick to judge. We wish they would be more accepting of any family who is dealing with mental illness, accepting and supportive.

Thank you to my parents for giving me unconditional love, support and understanding and for their many prayers throughout all my ups and downs with OCD. Without their care and help I would not be where I am today.

ONLINE SUPPORT

OCD-Support (<http://health.groups.yahoo.com/group/OCD-Support>)

This is a very large and well-connected support group. Among its many members are doctors and treatment professionals who respond to questions.

OCD-Family (<http://groups.yahoo.com/group/OCD-Family>)

This is a mailing list for the loved ones of OCD sufferers, a safe place to discuss OCD and the way it affects the family as well as the sufferer. Its purpose is to help learn new ways of dealing with OCD from a second-hand perspective and to learn how to help our loved ones. It is asked that OCDers themselves not subscribe to this list.

OCD and Parenting (<http://health.groups.yahoo.com/group/ocdandparenting>).

An online support group for parents of children with OCD.

Organized Chaos (<http://www.ocfoundation.org/organizedchaos>)

For teenagers/young adults only, this is a site for learning about OCD from each other, and from treatment providers.

JJ's Place (www.jjsplace.org)

The website for kids with OCD. Also has resources for family and friends, teachers, and therapists.

For a long list of websites relating to OCD, see our website at www.ocdmich.org.



Compulsive Hoarding in Older Adults: The Family's Perspective

by Elizabeth Nelson

Compulsive hoarding has long been associated with the elderly; it is often identified as a symptom of dementia. At one time, experts theorized that hoarders of a certain generation acquired their habits and behaviors from having lived through the Depression. Current research recognizes that many older people suffer from a compulsive hoarding disorder, unrelated to dementia or the trauma of chronic deprivation. For many-- perhaps most-- the disorder begins in middle-age or earlier and grows worse over the course of years and decades.

Among the estimated three million Americans who compulsively hoard, age defines a very serious problem. Over time, the volume of clutter increases, while the person's physical strength (i.e. ability to navigate the home) decreases. Among people 65 years and older, falls are the leading cause of injury deaths and the most common cause of nonfatal injuries and hospital admissions for trauma (Center for Disease Control, 2006). High levels of dust threaten the respiratory health of anyone who lives in a heavily hoarded home.

In the media, we sometimes hear shocking stories of elderly persons found dead, in dangerously cluttered homes. A common scenario is the case of fire, when rescue workers cannot access a home or-- in more severe cases-- someone is literally crushed by her own belongings in a frantic rush to escape. Public reaction to these stories often includes the question: Where was his/her family? or How could the family let him/her live that way? or Why didn't anyone step in and help?

For families trying to care for a loved one who hoards, these questions are both painful and frustrating. Many of us are available, but shut out. Many of us don't want to see our loved ones living this way, but we can't stop them. Many of us have tried to offer assistance, but our loved ones refuse it. I help lead a support group for adult children of hoarders (www.childrenofhoarders.com) which now has over 700 members. We exchange stories of loved ones who have struggled with hoarding for years or decades (coping in secret) and now face a crisis. At its core, compulsive hoarding is an anxiety disorder: sufferers feel intense responsibility for their possessions and exercise extreme control over them.

Until very recently, there was so little information about hoarding disorder that most families did not know how to talk about the problem, much less how to address it. Hoarded homes in the context of a family can too often look like lazy housekeeping and-- when faced with such an accusation-- many compulsive hoarders offer explanations that are hard to refute ("You kids are messy" or "I don't have time to deal with it right now" or "I'll get to it eventually"). Our members report hearing many of the same excuses throughout childhood, as a compulsive hoarder (confused and overwhelmed by the problem) attempts to both minimize the issue and evade responsibility for it.

Over time, the family living with the disorder develops a habit of relating to one another. The compulsive hoarder argues most vehemently and aggressively that no one is 'allowed' to interfere with the excess clutter in the home and children, especially, are trained to keep visitors out to avoid embarrassment; those who grow up in such a household eventually accept the rules of "Don't touch" and "No visitors" as the irrefutable status quo. Even into adulthood, children of hoarders are reluctant to defy these rules. Agencies that provide services to the elderly need to understand this family dynamic of secrecy when they receive reports of hoarding. Exposing the problem feels like a terrible betrayal; family members are likely to avoid reporting it until the conditions are very severe.

Even the most extreme hoarding behavior can be hidden inside the home where no outsider would ever see evidence of it. This contrast between inside/outside identities (the 'double life') presents an even greater chal-

(Continued on page 6)

lunge to families trying to persuade a hoarder to seek help. When only close family ever suggests that the hoarder has a serious problem, it can seem that 'no one else' shares the concerns. We see our parents rely on the opinions and ideas of casual acquaintances ('outsiders') much more readily than those of the close family members who have seen and know the home situation. Compulsive hoarding thrives where it can hide; many hoarders will not practice the behavior in places where it will be seen by outsiders. Families do not want to humiliate or embarrass the compulsive hoarder in their lives, but we also realize that someone (other than us) must see the conditions and offer strong assessments before many of our loved ones will ever contemplate change.

Our group sometimes compares hoarding disorder to an addiction but, unlike other addictions, we have no model for intervention. Reports from our members confirm that, often, outsiders (e.g. city home/health inspectors, social workers or other public 'authorities') are the only motivation for a hoarder to improve the physical conditions of the home. Outsiders play an important role in both persuading the hoarder to seek help and pressuring the hoarder to alter everyday habits. There is no simple treatment or cure for compulsive hoarding, but in many cases it is possible to assert boundaries and maintain enough clear space to keep the home minimally safe.

Even the most current research does not provide specific protocols for managing a crisis. When asked "What can I do?", experts consistently repeat the same warning over and over again: do not discard a hoarder's belongings and do not clean without their consent because this will only upset them. This warning is not useful for the family whose loved one is living in dangerous conditions. Where research is silent and community resources scarce, families are forced to improvise solutions that will keep a loved one safe.

For neighbors, healthcare professionals, and social service providers who see compulsive hoarding disorder in their own communities, we offer the following recommendations:

- Take reports of hoarding seriously. Our members find that, without the evidence of photos, social workers and health professionals are often reluctant to believe their descriptions of home conditions. If you learn about hoarding disorder from a family member, it is almost certainly near crisis-point.
- Ongoing visitation is as important as the initial efforts necessary to make a home environment safe. Many communities already have hoarding task forces in place to coordinate mental health services and other in-home therapy that will prevent a crisis before it happens (again). Hoarding disorder is best treated as a chronic health issue that requires continuing care and services.
- When possible, try to work with family members to find solutions and strategies that work. What you hear and see from the person suffering from the disorder is not likely to be an accurate reflection of the problem in the home. The shame and embarrassment associated with this is still very strong and, understandably, many compulsive hoarders cope by minimizing the behavior as much as possible.
- Consider what assistance you can provide to families actively trying to address safety hazards within a home. Family efforts to set boundaries and create safe living space for a loved one will only work if the compulsive hoarder can accept them. When a loved one is isolated in a dangerously cluttered home, families often feel that they have only one very unappealing option to get outside support: the drastic step of reporting a family member to APS for self-neglect.

For more information about compulsive hoarding disorder, visit www.helpinghoarders.com and if you are a family member in need of support, visit www.childrenofhoarders.com.

Cruel Obsessions

By Heidi VanDenBerge

Were these intrusive, horrific thoughts really just thoughts, or was I going crazy? I honestly thought I was just going crazy and my life was doomed. Thoughts of taking a knife and stabbing my two precious children consumed my mind every day and night. It was like a broken record. These thoughts kept playing over and over in my mind. There was nothing I could do to rid myself of them no matter how desperately I tried.

What was happening to me? I had everything I've always wanted in life. I had an amazing husband, and two beautiful little girls. Why was I having thoughts of loosing it all, and doing something so against my beliefs and dreams?

My heart and my mind were at war. I loved my two girls more than anything. All I have ever wanted for them was the best, but my mind was trying to tell me different. I was so disgusted with myself. I became so ashamed and felt so dirty. I hated myself. So I made my mind switch the thoughts from hurting my children, to hurting myself. So if I ever gave into these evil thoughts and picked up a knife, before I could make it to my girls, I would stab myself instead.

I lived with this misery on my own for months. There was no way I was going to let anyone know about these. How could I? My husband would leave me and take our girls with him. Everyone would look at me with disgust in their eyes, and I would be left all alone in this world. I couldn't risk this happening, so I knew I had to suck it up and deal with this on my own. I just prayed these thoughts would go away on their own.

Well of course they didn't. They actually became more intense as the days went by. These thoughts were so strong, making me feel I had to give in to them. I couldn't eat, I couldn't sleep, and I never wanted to be around my girls. I was frightened of myself, and terrified of what I was capable of doing.

Still everyday, I would wake up and put a smile on my face acting like normal, happy go-lucky Heidi. No one had any idea I was loosing it on the inside. That is exactly how I wanted it... until one cold, snowy afternoon in February of 2007.

I woke up that morning knowing it was going to be another nightmare of a day, and I was so sick of it. I wanted my life back, but felt hopeless. I remember bringing my oldest daughter to school, coming home and putting my youngest daughter down for her nap. I went to sit in our living room chair with these thoughts of stabbing myself running through my mind over and over again. My heart began to race and it was really hard for me to breathe. I was shaking

uncontrollably, and my whole body, especially my hands felt like they weighed a ton. It was as if I was trying to hold myself down from going into the kitchen to grab a knife. I began weeping, feeling this was it. This was the day the thoughts were going to win. I knew at the time that I had to do something about this, or I was going to do something I knew in my heart, I did not want to do.

From somewhere way down deep within me, I found the strength to call my mom and tried to spit out the words through my tears to her that I felt I was going to take a knife and stab myself. She was petrified and told me to hold on for three minutes, and she would be right over.

That day, my mom was my angel. She held me tight and told me everything was going to be okay. I am so thankful God made my mom answer her phone and be so close to my house that day. I truly believe she was there to save my life.

On that wintry day, I realized I needed help. I didn't want to live this way any longer. So I ended up checking myself into a hospital for people with mental illnesses named Pine Rest. Come to find out, I have been living with this monster called OCD. I never knew, until that point, that OCD could be so brutal. I have to admit I was a bit relieved to hear I wasn't just going crazy or insane.

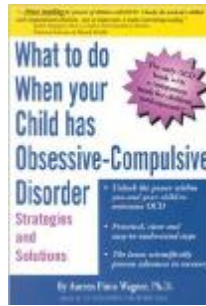
I was amazed at how gracious and supportive my family and friends were. My husband stood by my side through this crazy time in our lives. Of course he was scared and unsure of the future, but he never stopped loving me. I am glad to tell you that with the help of Pine Rest, medication, therapy, and most importantly to me God, my OCD is now under control. I finally have my life back! I no longer live in fear. The future which at one point looked so gruesome now excites me. Every morning I wake up, I cannot wait to kiss my girls and tell them how much I love them and actually feel this love again. It's so easy to take life for granted until it's almost wiped from under your feet. I thank God for everyday he gives me free from those dreadful thoughts.

So why do I share my story with you? To give those of you struggling with your OCD on a daily basis, hope. If you are just hanging on by a string, keep holding on. Don't stop fighting, because it can get better. Trust me, I know it's a hard fight, and at times, it just plain stinks. I still have things to work on myself. I have been able to use knives again, but still fear to keep them in my house. I wonder if I'll ever be able to have them in my house ever again, but I just have to believe that someday, I will get to that point.

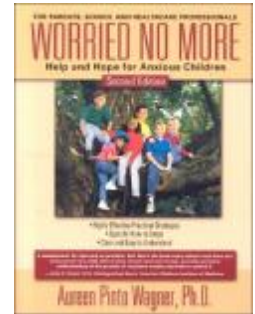
So I urge you to keep on treading, and remember that tomorrow is a new day. You have to believe that it can only get better from here. I wish you the best!

SUGGESTED READING

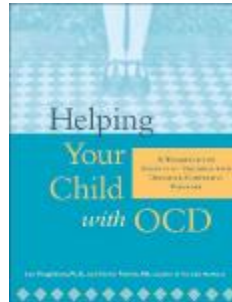
Aureen Pinto Wagner, Ph.D.
*What to do When Your Child has
 Obsessive-Compulsive Disorder:
 Strategies and Solutions*
 Lighthouse Press, Inc., 2006
 ISBN-13: 978-096773471-2



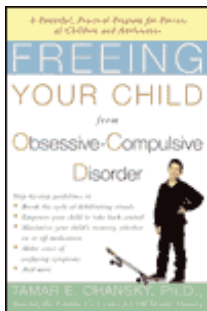
Aureen Pinto Wagner, Ph.D.
*Worried No More: Help and Hope
 for Anxious Children*
 Second Edition
 Lighthouse Press, Inc., 2005
 ISBN-10: 0-9677347-9-7
 ISBN-13: 978-0-9677347-9-8



Aureen Pinto Wagner, Ph.D.
*Treatment of OCD in Children and Adolescents:
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 (888) 749-8768
www.Lighthouse-Press.com



Lee Fitzgibbons, Ph.D., Cherry
 Pedrick, R.N.
*Helping Your Child with OCD:
 A Workbook for Parents
 Of Children with Obsessive-
 Compulsive Disorder*
 New Harbinger Publications, 2003
 ISBN: 1-57224-332-5



Tamar E. Chansky, Ph.D.
*Freeing Your Child from Obsessive-
 Compulsive Disorder*
 New York: Crown Publishers, 2000
 (Hardcover)
 ISBN: 0-8129-3116-5
 New York: Three Rivers Press, 2000
 (Paperback)
 ISBN: 0-8129-3117-3

Daniel A. Geller, MBBS, FRACP
 "Obsessive-compulsive and spectrum disorders in
 children and adolescents"
Psychiatric Clinics of North America
 Vol. 29, 2006, Pages 353-370

WORDS OF WISDOM

Insanity: doing the same thing over and over again and expecting
 different results.
- Albert Einstein

*Courage is the resistance to fear, mastery of fear - not absence
 of fear.*
- Mark Twain

Life is either a daring adventure or nothing. Avoiding danger is no safer
 in the long run than exposure.

- Helen Keller

BULLETIN BOARD

Worry Workshop

Does your child have excessive worries about:

- bad things happening?
- the weather?
- new situations?
- health and illness?

Do these worries make it hard for your child to:

- go to sleep at night?
- go to school?
- be away from you?
- be happy?

Have you tried and failed using:

- reassuring?
- reasoning?
- accommodating?
- threatening?

THEN YOU SHOULD ATTEND THIS WORKSHOP.

Offered by Dr. Antonia Caretto, this three session small group workshop is for children ages 7-13 with excessive worries and related difficulties in managing anxiety.

- Each session lasts seventy-five minutes.
- Children and parents attend each of the sessions together.
- Participants receive a 30-page workbook.
- Materials include information for kids and adults.
- Each session begins with an outline for note taking and ends with a homework task.
- Activities will be completed in the workshop and at home.
- Approximately twenty tools and concepts will be presented over the course of the three session workshop.

Workshop dates are Saturdays, January 5, 12, and 19, 2008, and will be held at Dr. Caretto's office at 25882 Orchard Lake Road in Farmington Hills. For more information, go to www.betreatedwell.com/worry.html. To register, call 248-553-9053.

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Advertise with us

Treatment professionals, what better way to find the OCD sufferers who need your help, and to give them a way to find you. Just place your business card in *Never Say Never*, the quarterly newsletter of the OCD Foundation of Michigan. For just \$25.00 per issue, your card can be in the hands of the very people who need you most. It's a great way to reach out to the OCD community, and at the same time support the OCD Foundation of Michigan. Send your card to OCDFM, P.O. Box 510412, Livonia, MI 48151-6412, or e-mail to OCDmich@aol.com. For more information, call 313-438-3293.

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- Obsessive-Compulsive Disorder
- OC Spectrum Disorders

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616.940.9091 alan.carriero@sbcglobal.net

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COULD BE HERE!

PLEASE HELP

The OCD Foundation of Michigan is funded solely by your annual membership fees and additional donations. We have no paid staff. All work is lovingly performed by a dedicated group of volunteers. **WHY NOT VOLUNTEER YOUR TIME?** Call 313-438-3293 or e-mail OCDmich@aol.com.

The OCD Foundation of Michigan Membership Application

Please Print:

Name: _____

Address: _____

City: _____ State/Province: _____ ZIP/Postal Code: _____

Phone Number: _____ E-mail Address: _____

May we send you notices and announcements via e-mail? _____

- Enclosed please find my check for \$20 annual membership fee.
- Enclosed please find an additional donation of \$ _____

Make check or money order payable in U.S. funds to
Terry Brusoe, Treasurer
THE OCD FOUNDATION OF MICHIGAN
25140 Docksider Lane
Harrison Twp., MI 48045-6707

12/2007

Please Don't Throw Me Away

You've finished reading me and don't need to keep me anymore. Or worse (boo-hoo), you don't need me and don't even want me. In either case, please take me somewhere where I can help someone else. Take me to your library. Take me to your doctor, therapist, or local mental health clinic. Take me to your leader. But please, please, don't throw me away.



OCD Foundation of Michigan Mission Statement

- ◆ To recognize that Obsessive-Compulsive Disorder (OCD) is an anxiety-driven, neurobiobehavioral disorder that can be successfully treated.
- ◆ To offer a network of information, support, and education for people living with OCD, their families and friends, and the community.

**IF YOU WOULD LIKE TO BE ADDED TO OR DELETED FROM THE MAILING LIST
PLEASE CONTACT US**

The OCD Foundation of Michigan
P.O. Box 510412
Livonia, MI 48151-6412