TEN YEARS OF NEVER SAY NEVER

I was looking over the early issues of Never Say Never recently when I realized that 2005 is the 10th Anniversary of this newsletter. I also noted that there have been some outstanding articles within these pages over the past 10 years, and we thought it would be appropriate to reprint some of those gems in this and future issues.

In this issue, we have included two articles from the Inaugural Issue dated July 1995. Look inside for Defining the Experience of OCD, Part 1, by Bob Cato, and The Bright Side of OCD, by Debra Dahl. We also have Part 2 of the series Obstacles to Treating OCD, by Drs. Antonia Caretto and Jessica Harrell.
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July 1995:
Defining the Experience of OCD, Part 1, by Bob Cato.
The Bright Side of OCD, by Debra Dahl

March 1996:
Defining the Experience of OCD, Part 3, by Bob Cato.
Planting Seeds of Hope, by Wally Green

June 1996:
Defining the Experience of OCD, Part 4, by Bob Cato.
When the Black Dog Bites, by Wally Green.

December 1996:
OCD Symptoms, by Bob Cato
Nothing Lasts Forever, by Wally Green

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* Thanks to Mark Fromm, president of Downriver Marketing LLC, 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:
2nd Wednesday, 6:30-8:30 PM
Washtenaw County Community Mental Health
Call Mary Jo at (734) 761-9167

DEARBORN:
1st 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

FLINT:
1st and 3rd Thursdays, 7-9 PM
Perry Center
11920 S. Saginaw St.
Grand Blanc
Call Mario at (810) 743-8508

GRAND RAPIDS:
Every other Wednesday, 7-9 PM
OCD and other Anxiety Disorders
Dominican Center, Marywood Campus
Fulton Street
Call Mike at (616) 957-5119

HOLLAND:
For information, call:
Geraldine at (616) 335-3503 or
Tony at (616) 396-5089

LANSING:
1st and 3rd Thursdays, 7:00-9:00 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 Cyndi at (248)-541-0782

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

CLEVELAND, OHIO:
2nd and 4th Thursdays
Call Mary Ann at (440) 442-1739

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.

Organized Chaos (http://www.ocfoundation.org/1000)
For teenagers/young adults only, this is a site for learning about OCD from each other, and from treatment providers.
After presenting the fundamentals of Exposure and Response Prevention (ERP) in the last newsletter, the focus of this article (#2 of 3) will be on challenges to implementing that treatment. It is important for clinicians, patients, and their families to recognize potential roadblocks that may interfere with progress in treatment. While some of these roadblocks may be more common and easy to identify, some obstacles are rather obscure. They all require treatment modifications, which are not identified in Exposure with Response Prevention protocols and must be uniquely tailored to fit the individual.

Chronic tardiness and/or trouble keeping appointments is one of the more common problems seen in treating OCD. Performing rituals can consume large portions of the day which, not surprisingly, interferes with other obligations such as work, school, and even therapy. Therapists have different ideas about the importance of consistent attendance or tardiness. It is our belief that consistency and accountability are essential components of treatment. Patients need to know that it is not acceptable to ritualize during their scheduled appointment times.

One strategy that may be used to increase on-time and consistent attendance is to “hypothetically” schedule appointments 1/2 hour before their actual start times. This gives patients some cushion if OCD symptoms increase unexpectedly. Another approach is to “give permission” for patients to ritualize for a specified period of time just before coming to therapy.

Sometimes, however, attendance and/or tardiness problems persist and must be dealt with via clear and concise limit setting. One approach is to let a patient know that if he arrives more than twenty minutes late, he will not be seen. Because adequate time is needed to conduct an effective ERP session, it is important to avoid abbreviated therapy hours. Not only does conducting a shortened session reinforce the late behavior but also allows patients to avoid prolonged anxiety exposure that is so crucial to ERP.

In more severe cases of OCD, there may be a tendency to abandon normal daily routines. For example, a person with OCD may choose to sleep all day and stay up all night, allowing him to obsess and ritualize at length. Even when patients live with others (e.g. spouses, parents, etc.), this “vampire” schedule significantly reduces and/or eliminates accountability. That is, there is no one to observe, comment on, offer distraction, or provide support during the night, and the result is almost always an increase in the severity of symptoms.

In addition, sleeping all day decreases exposure to light and limits opportunities for socializing and engaging in productive activities. All of these increase the risk of depression for a group already at high risk for depressive symptoms. Families often need therapeutic guidance and support to change these routines, just as they do when targeting compulsive behavior.

The family of the OCD sufferer is typically over involved with the disorder. Families that include an OCD sufferer frequently experience a microcosm of the disorder, reporting intrusive anxiety and ritualistic responding.

Some families cope by enabling. This may be done via denial and avoidance of the problem, accommodating or engaging in the rituals, or giving reassurances. Other families cope by expressing hostility. It may be seen via debating, arguing or threatening, or just maintaining a rigid family culture that colludes in the resistance to change.

Albeit not helpful, these responses are natural. The family as a whole must come to tolerate uncertainty, just as the patient is asked to do. The first step in working with a family is to promote dialogue about the disorder. Only after the family members are all ‘speaking the same language’ can they truly provide mutual support for the ERP process.

One group of patients that can present some unique challenges are children between the ages of 9 and 12. The reason for this is not entirely clear, but it is likely, in part, due to the level of cognitive development. ERP is facilitated by an understanding of 1) the irrationality of obsessions and/or compulsions and 2) the concept of short-term discomfort needed for long-term anxiety relief. Many pre-adolescents do not recognize the irrational nature of their OCD worries and have an even more difficult time grasping the notion of intentional exposure to that which creates such fear in them. Therefore, resistance to treatment is quite high. A strong therapeutic alliance, anchored in trust and support, can help lessen this resistance.

Occasionally, the obsessions themselves become an obstacle to treatment. For instance, a patient (usually a child) might explain that his OCD won’t let him talk about his obsessions or compulsions. Dealing with this can be especially difficult. To begin, it is important to re-frame the complaint to empower the patient; therefore, rather than saying “my OCD won’t let me tell you”, he could say “I am choosing not to tell you about my obsessions and compulsions”. The message here is that the OCD does not make the rules, and patients need to, deliberately and consistently, challenge such a notion. Once this framework is adopted, treatment often progresses steadily.

Sometimes a child may report that all hierarchy items (i.e. feared situations) are “ten” on a zero to ten scale of Subjective Units of Distress or “fear thermometer”. This seemingly rigid roadblock to ERP can be addressed

(Continued on page 8)
Defining the Experience of OCD
By Bob Cato
(from the Inaugural Issue, July 1995)

In attempting to define the experience of having OCD, one has to not only look at the various symptoms themselves, but also focus in on the emotional and spiritual ramifications affecting the sufferer. While the severity of the disorder may range from mild to extreme impairment of functioning, the devastation to the human spirit is immense. Those persons afflicted report loss of self-esteem, family difficulties, feelings of being totally alone with this disorder, and the high cost of terrific battles in fighting their obsessions and rituals. Intellectually realizing that a thought is totally irrational does not in any way have an impact upon the person’s ability to fight OCD. The disorder always throws in the “what if?” consequences, thereby feeding the subject’s doubt and thus propelling him on an endless quest for certainty in his life.

Although OCD is a physically based brain disorder and has proven to be biochemical and genetic in origin, as well as the result of Encephalitis, Sydenham’s Chorea, and closed head injuries in some cases, it is important to acknowledge that the symptoms themselves are the disease and do not hide some long ago forgotten trauma in childhood as the neo-Freudians once proposed. Rather, it is only when either or both anti-obsessional medication and behavioral modification are employed that recovery can begin.

In my own research of the subjective experiences of those suffering from this disorder, I have found eight major themes. These include anxiety, doubt, perfection, magical thinking, alienation, embarrassment, shame, and feelings of torture. The first four seem to motivate and empower the disorder, while the remaining themes seem to be the emotional and spiritual ramifications of the struggle with OCD.

Anxiety is a great motivator behind OCD and often may include not only panic attacks leading to phobic avoidance, but also a sense if inaccurate risk assessment. Doubt is pervasive throughout OCD and includes not only the physical senses of sight, sound, and touch, but also doubt over the quality of performance, regardless of the task. In perfection, there is a need to be precise and correct as well as often a need for symmetry and order. In some, magical thinking promotes fears of thoughts and actions irrationally affecting others and their safety.

The remaining themes seem to be the result of struggling with OCD. Alienation causes feelings of loneliness and isolation as well as a sense of being different than others. Embarrassment is caused by the painful awareness of the irrationality of the symptoms and the need for secrecy. Shame results from the inability to stop intrusive thoughts and rituals, leading the sufferer to feel he is either a bad person or weak. The feelings of torture are similarly connected to the feeling that this disorder never lets up. Fortunately, with the proper use of medication and behavioral modification, these last four themes and the precipitating themes improve dramatically as self-esteem and confidence are regained. In future issues, I would like to explore these themes in more detail.
THE BRIGHT SIDE OF OCD

By Debra Dahl

(from the Inaugural Issue, July 1995)

Anyone who has ever lived with OCD is acutely aware of the struggles, anxieties, and often the heartbreaks of the disorder. However, how many people believe that there can be a bright side of OCD? Personally, I believe that the “bright side” is hope - the hope that is ahead for anyone who suffers from this dreaded enemy. It is my intention to dispute the claims that it is impossible to live a fulfilled life in spite of OCD. Below are several suggestions for coping effectively with the difficulties of the disorder.

1. Recognize that you are in a battle. No one in combat has ever embraced his or her enemy, so why should you?
2. You set the rules of the game, not the enemy.
3. Realize that everyone alive has problems and struggles that we all must deal with. But remember - it is not important what difficulties we face, but how we deal with them.
4. Believe it or not, struggles do produce character. Think of a young tree planted in the ground. It appears frail, and as the storms surround it, one may think it will never survive. However, if the tree is planted in rich soil, it grows into a strong beautiful wonder. Just like the tree, if we continue to persevere and not be taken back each time we face the difficulties of OCD, we too will grow into the wonderful people we were created to be.
5. Keep pressing toward the goal of a brighter tomorrow. Never give up and only spend time in the past if it will help you move forward. Otherwise shake the dust off your sandals and move ahead.
6. Have you ever heard it said that “helping someone else can be the best medicine”? I believe that rather than dwell on our difficulties, share an experience with someone else who might be going through the same situation. You would be surprised how encouraging you can be to them and what a blessing it can be to you.
7. Never be ashamed. If your friend had an illness, such as diabetes, would you think that he or she caused the illness? Of course not! So stop blaming yourself, and most of all remember - OCD does not make you a bad person.
8. You are not alone. There are more people with OCD than you think! OCD does not have to be debilitating, nor does it have to keep anyone in bondage. Once again the key is knowing how to deal with the difficulties and not the problems themselves.

Once there was a man with OCD who worked very hard to do everything “right” (according to his standards). Never could he accomplish his goal because nothing was “good enough for him.” Not only did the man become frustrated, but he was very unhappy. One day he opened his Bible and was “set free” by the verse that told him he is saved, not by his works, but by faith in God (Ephesians 2:8). In spite of his disorder, Martin Luther was able to overcome the difficulties of OCD and began the Reformation.

Of course, coping with OCD can be an uphill battle; however, I am convinced that with faith and hope, a “brighter tomorrow” can be attained. Our world still needs a lot of changing; you may just be the one to change it.
In August of 1997, the OCD Foundation of Michigan held its first weekend camp for kids suffering from OCD. “Camp Redwing”, named for the boyhood home, now Bed and Breakfast, of OCDFM Founder Wally Green, offered a weekend of companionship and camaraderie for the kids. Located on beautiful McKeen Lake in Columbiaville, north of Lapeer, Redwing was a place where the kids could escape and have some fun. There was tent camping, swimming, boating, and fishing, pancake breakfasts and sing-alongs around a campfire. Some OCD talk and behavioral therapy was provided by the area’s best treatment professionals, who volunteered their time to benefit the kids.

Camp Redwing became an OCDFM tradition, continuing for six years, until August of 2002. But by that time, it was becoming more and more difficult to plan and run the camp as our pool of volunteers began to dry up. By 2003, it became apparent that we did not have the resources necessary to continue sponsoring the camp, and regrettably, we had to cancel the event that year and in 2004.

Well, as the saying goes, “WE’RE BAAAAACK”. And Camp Redwing 2005 will be better than ever, moving this year to the beautiful Howell Conference and Nature Center in (where else?) beautiful Howell, Michigan.

We will be providing more information as it becomes available. For now, just . . .

SAVE THE DATE - Aug 12-14, 2005

“People are like stained-glass windows. They sparkle and shine when the sun is out, but when the darkness sets in, their true beauty is revealed only if there is a light from within.”
- Elizabeth Kubler-Ross

"A pessimist sees the difficulty in every opportunity; an optimist sees the opportunity in every difficulty."  - Winston Churchill

"Nothing can stop the man with the right mental attitude from achieving his goal; nothing on earth can help the man with the wrong mental attitude."  
- Thomas Jefferson

"One can never consent to creep when one feels an impulse to soar."  
- Helen Keller
Obstacles to Treating OCD: Part 2
(Continued from page 4)

by surreptitiously doing graded exposure with these hierarchy items in treatment sessions; for example, by addressing the anxiety-provoking stimuli for longer and longer portions of appointments via conversation and drawing.

In both the “my OCD won’t let me tell” and the “everything is a ten” examples of obstacles that children may present, the underlying fear might truly be about “being wrong”. If so, treatment must ultimately address this anxiety, not just the items identified on the hierarchy. These types of second layer obsessions are also likely in situations where children (and adults) seemingly comply with the ERP but fail to progress.

As you can tell, a skilled clinician must not only know how to administer the mechanics of ERP but must also be able to identify and treat both the roadblocks, which read like a roadmap, as well as obstacles that may be more obscure.

Our next article will focus on both common and not-so-common obsessions. We will also discuss how to treat individuals who experience obsessions only, with little or no accompanying compulsive behavior.
Support is a good thing.

Are you a small business owner? Better yet, are you a BIG business owner? There are lots of things you can do to support the mission of the OCD Foundation of Michigan. Some examples:

- COMPUTER SERVICES? Help us build and maintain a better web site.
- OWN A PRINTING BUSINESS? Print our newsletter.
- OWN OR LEASE A BULDING? Provide us some office space in your building.

We are grateful for any support you can provide. AND WHILE WE’RE ON THE SUBJECT, WE WANT TO ACKNOWLEDGE A SPECIAL FRIEND:

Thanks to Mark Fromm, president of Downriver Marketing LLC, for his support over the years. He has generously donated his services in securing and maintaining our domain name (ocdmich.org) and hosting our website.

HELP WANTED

Do you have a few hours per month, and are you ready to dedicate some time to further the cause of OCD education and support in the State of Michigan? Why not volunteer to join the OCDFM Board of Directors?

YOU CAN MAKE A DIFFERENCE!

Call 313-438-3293 or e-mail OCDmich@aol.com

A New Way to Contribute
Donate your car to Charity Motors

The OCDFM is now one of the non-profit organizations participating in the Charity Motors Car Donation Program. You can donate a car you no longer need or want, receive a tax deduction, and designate “The OCD Foundation of Michigan” to receive the proceeds from the sale of your car. If you are interested in participating in this program, please call Charity Motors at (313) 255-1000 or visit them on the web at charitymotors.org, and designate “The OCD Foundation of Michigan” as your charity.
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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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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.

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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 OCD is an incurable neurobiological disorder that can be treated with great results by the reduction of anxiety that OCD creates.

♦ To offer a network of information, support and education of parents, teachers, friends, family, and the medical community.

♦ To enlighten state legislators on how this disorder affects the sufferer, on entitlements under the full umbrella of the State Board of Education and the laws of the State of Michigan.

IF YOU WOULD LIKE TO BE ADDED TO OR DELETED FROM THE MAILING LIST
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