

## Dr. Jenike Appeals for Research Funds

Dear Friends,

This past year is one of unprecedented achievement for the national Obsessive Compulsive Foundation. With Patti Perkins-Doyle,

one of the founders of the Foundation, serving as Executive Director, and Janet Emmerman as president and a rededicated and energized staff, we have a top flight group that has fine tuned the OC Foundation into a forward-looking and productive organization. Major fundraising efforts are underway, and there have been some

successes in raising monies for research into OCD and related disorders. However, only the sufferers and their families can understand the true pain of the disability caused by these disorders, and we need your educated help in raising money for this year's research grants. I have been approached by many researchers throughout the country about whether or not significant funds will be available. If we can raise large amounts, we will be able to convert dozens of brilliant young people to OCD research.

For the last few years, I have made a plea for help regarding the research efforts of the OC Foundation. I heartily thank those of you who have responded. However, the funds raised last year were quite modest. We were only able to raise a total of \$82,000 from the entire country for research. This year so far, we have raised \$95,000 which is a little better, but we need much more.

With the monies that are raised, we fund

research proposals that are submitted by talented researchers around the world. Members of the OC Foundation's Scientific Advisory Board rank the proposals to be sure

that the finest are funded. Last year we were only able to fund 5 projects out of a large group of worthy applications. The only thing holding us back from progress in these disorders is the lack of research funding. We have skilled researchers and they have promising projects. Unfortunately, these talented people will look elsewhere and work on

other disorders if we do not provide the needed funding.

Many organizations like the OCF have become major funders of high quality research, including NARSAD, Tourette Syndrome Association, and the Alzheimer's Association. These others have raised many hundreds of thousands of dollars for research about their disorder. Many of the world's best researchers decide to study particular disorders based on the availability of funds. To attract them to OCD research we will need to offer them more research dollars.

Contribute to the OCF Research Fund to help us to find the causes of OCD and to develop effective treatments for everyone.

Thank you,

Michael A. Jenike, MD  
Professor of Psychiatry  
Harvard Medical School  
Chair, Scientific Advisory Board



## Call for Conference

The 8th Annual OC Foundation Conference is scheduled for July 20-22, 2001 in Denver, CO. Anyone interested in doing a presentation at the Conference is urged to submit his/her proposal now. The deadline for submissions is January 17, 2001.

The Conference Planning Committee has decided that there will be three tracks focusing on three separate

**Submit your  
proposals by  
January 17, 2001**

groups: people with OCD, children and adolescents with OCD, and their families and treatment providers. The Committee is interested in programs that will appeal to these groups. Topics that are of special interest are: scrupulosity, comorbid conditions, spectrum disorders including BDD and hypochondriasis, help for families, help for treatment resistant OCD, and recent research advances.

For the official proposal form, call Jeannette Cole at 203.315.2190. Only submissions on the official form will be considered.

## BTI's Train 77 New Therapists

The Foundation sponsored the first set of overlapping Behavior Therapy Institutes November 12-16 in Oakland, CA. Seventy-seven therapists from Kaiser Permanente of Northern California attended three overlapping behavior therapy training sessions. This unique arrangement was developed by C. Alec Pollard, Ph.D., director of the Foundation's Behavior Therapy

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# Bulletin Board

## Thinking Processes in Body Dismorphic Disorder

This is an on-going study at Massachusetts General Hospital.

People with Body Dismorphic Disorder (BDD) often experience such high levels of distress about their appearance that their ability to function in daily life is impaired. The purpose of this study is to find out more about cognitive functioning in patients who suffer from this problem.

As part of the study, participants will be asked to make two separate appointments. During the first visit, eligibility for the study will be determined through a psychiatric screening interview. This interview requires from 15 to 45 minutes. There will also be a photo taken of each participant, which will be used in the study. Only the participant and the study team will see this photo. The photo will be destroyed after the completion of the study.

The tasks conducted during the second visit will test cognitive functions, such as, memory and perception. Participants will be asked to fill out several questionnaires assessing anxiety, mood and BDD symptoms. The second visit will take approximately 3 hours. Participants will receive \$35 for their participation.

**ELIGIBILITY:** Participants must be between 18 and 65 years old and suffer from BDD.

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## Anxiety Disorders Meeting Open to Patients and Family

The Bio-Behavioral Institute is sponsoring an all day conference on ANXIETY DISORDERS on January 27, 2001 at the Long Island Marriott Hotel and Conference Center in Uniondale, Long Island.

Guest lecturers will be Dr. Jack Gorman from Columbia University, Dr. David Spiegel from Boston University, Anne Marie Albano from New York University Child Study Center and Drs. Jose Yaryura-

Tobias and Fugen Neziroglu from the Bio-Behavioral Institute and New York University.

This lecture is free of charge, but seating is limited. Please call (516) 487 7116.

## Genetic studies in OCD

The laboratory of Human Neurogenetics at The Rockefeller University in New York is currently investigating the genetics of OCD. A recent study conducted by our group revealed one of the genes associated with increased susceptibility to OCD, but more research is needed.

The study we are currently conducting requires a small amount of blood from individuals with OCD. This is a family study and it involves participation of at least two individuals from a family who have been diagnosed with OCD or families in which a child has been diagnosed with OCD and both parents are available to give blood samples. Other family members may also be invited to participate. This study is open to both children and adults. A telephone interview with a study clinician is also needed. There is no cost to participate and the University will cover the cost of the blood draw. This can be done near your home and the University will pay for the shipping charges also. Travel is not required and confidentiality is insured.

For more information, contact Maude Blundell, MS, the genetic counselor and research coordinator for the study at 1.800.920.9100, press 1 or by e-mail at blundem@mail.rockefeller.edu.

## Yale Child Study Center

### Genetic Studies

At the Yale Child Study Center, we are conducting research with families in which there is at least one person affected with OCD. The goal of these studies is to find genetic and non-genetic factors that influence the onset and course of OCD. Genetic studies suggest that there are several forms of OCD, and at least for some patients OCD is familial. This means that having one affected family member increases the possibility of having other first degree family members affected as well. While there is no direct benefit to participants, we hope that these studies will contribute to a better understanding of the causes of OCD, therefore leading to more effective treatments. The project involves answering clinical diagnostic interviews and having a blood sample drawn (from which DNA is going to be extracted). The interviews and blood work can be done at the family's convenience.

For more information, please contact:  
Dr. David Pauls  
Yale Child Study Center  
1-877-YALE-OCD

## Dimensional Y-BOCS Study

At the Yale Child Study Center we are conducting a project designed to validate a new instrument for the assessment of OCD patients, the Dimensional Yale-Brown Obsessive-Compulsive Scale (DY-BOCS). This questionnaire is designed to evaluate the nature and current severity of obsessive-compulsive symptoms with a multi-dimensional approach. We hope that this dimensional approach to OC symptoms may be useful for improving clinical, genetic and neurobiological studies. It is also possible that using a multidimensional severity scale in treatment studies will reveal clinically relevant patterns of response. The interviews take approximately 2 hours to complete. In addition, each participant receives \$20 as reimbursement.

For more information, please contact:  
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## OCD NEWSLETTER

The OCD Newsletter is published six times a year.

Obsessive-Compulsive Foundation, Inc.

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Scientific Advisory Board

The Obsessive-Compulsive Foundation (OCF) is an international not-for-profit advocacy organization with more than 10,000 members worldwide. It's mission is to increase research, treatment and understanding of obsessive-compulsive disorder (OCD). In addition to its bi-monthly newsletter, OCF resources and activities include: an annual membership conference; popular website; training programs for mental health professionals; annual research awards; affiliates and support groups throughout the United States and Canada; referrals to registered treatment providers; and the distribution of books, videos, and other OCD-related materials through the OCF bookstore and other programs.



# Two Federal Programs To Assist Parents of Children with OCD: SSI and CHIP

By Edward N. Matisik, J.D.

The federal government has established two need-based programs that may offer assistance to parents of children with OCD who have low-incomes. One of the programs, Supplemental Security Income (SSI), has been established for a long time, while the Children's Health Insurance Program (CHIP) is a fairly new program.

## Supplemental Security Income

SSI was established by the Social Security Administration almost 25 years ago. SSI provides parents or guardians of severely disabled children with a monthly payment to help defray the costs of raising the child. Although the program is administered by the Social Security Administration, the program is quite different from the regular Social Security Disability program.

SSI is available to parents of children 18 years of age and younger who have "a marked physical or mental condition or conditions that can be medically proven and which result in marked and severe functional limitations" which is expected to last for at least 12 months. SSI regulations require that children with OCD have "recurrent obsessions or compulsions which are a source of marked distress" and which meet certain age dependent criteria. For children aged one year to the attainment of age three, their OCD must cause at least of the following to occur: (1) gross or fine motor development at a level generally attained by children no more than 1/2 the child's chronological age, or (2) cognitive/communicative functioning at a level generally attained by children no more than 1/2 the child's chronological age, or (3) social functioning at a level generally attained by children no more than 1/2 the child's chronological age, or (4) any two of the preceding three areas at a level generally attained by children no more than 2/3 the child's chronological age. For children aged 3 to 18, there must be marked impairment in any two of the following four areas: (1) age appropriate cognitive communicative functioning, or (2) age-appropriate social functioning, or (3) age-appropriate personal functioning, or (4) deficiencies of concentration, persistence, or pace resulting in frequent failure to complete tasks in a timely manner. Children applying for SSI benefits are required to undergo medical examinations as part of the application process and, if approved, undergo "Continuing Disability Reviews" every three years to determine whether or not the child is still disabled. Further, the

parent or guardian must demonstrate that the child is receiving medical treatment that is medically necessary and available for his or her disabling condition.

The amount of payments made to the parents of qualifying children is calculated according to a very complex formula which takes into account the parents' or guardians' assets and income. A number of states may supplement the federal SSI payment with additional payments. These states are: Arizona, California, Hawaii, Massachusetts, Nevada, New Jersey, New York, Pennsylvania, Rhode Island, Vermont, Washington, and the District of Columbia. Children who qualify for SSI may also qualify for Medicaid and state and local children's health programs. Parents who apply for SSI on behalf of their children automatically apply for the state supplemental payments-which are then added to the same check as the SSI payment if the child qualifies-when the apply for SSI, but some states require a separate application for Medicaid and other programs if the child is approved for SSI. For example, children in Massachusetts and California are automatically enrolled in Medicaid when their application for SSI is approved, but parents or guardians of children in Hawaii must file a separate application for Medicaid even if their child qualifies for SSI. Parents or guardians should check with their local Social Security office for the rules in their state of residence.

Parents or guardians should schedule an appointment with their local Social Security office to apply for SSI for their children by calling toll-free (800) 772-1213.

## Children's Health Insurance Program

As part of the Balanced Budget Act of 1997, Congress established the Children's Health Insurance Program (CHIP) to expand health insurance coverage for uninsured, low-income children. CHIP provides each state with federal funding to assist it in increasing health insurance coverage for children by expanding coverage through the state's current Medicare program or establishing a separate child health insurance program. All 50 states, the District of Columbia, and the five territories of the United States have each established their own CHIP.

States have a great deal of flexibility in establishing their own programs, so eligibility criteria and the amount of benefits available can vary greatly from state to

state. For example, Wyoming's CHIP provides the full package of Medicaid benefits to children age 6 to 19 in families with incomes at or below 133% of the federal poverty level. Families in Wyoming are not required to share any of costs of CHIP. Washington state, on the other hand, uses its newly established CHIP to provide medical coverage to uninsured children under the age of 19 in families with incomes between 200% and 250% of the federal poverty level. Washington charges families who have children enrolled in CHIP \$10 per month per child, up to a maximum of \$30 per month, and requires parents to make \$5 copayments for physician services and prescription drugs and \$25 for emergency room visits not resulting in an inpatient admission; Washington caps co-payments at \$300 per child per year or \$900 per family per year.

The legislation enacted by Congress to establish CHIP permits, but does not require, states to pay for inpatient mental health services, including services furnished in a state-run hospital, as well as at other 24 hour services. Funds may also be used for the payment of outpatient mental health services. Congress also required that the Mental Health Parity Act of 1996, which prohibits discrimination against mental health benefits with respect to annual caps and lifetime limits, apply to all the CHIP programs. Furthermore, the Mental Health Parity Act of 1996 requires that Chips provide mental health benefits equal to 75% of the mental health benefits provided in a state's basic health insurance plan (e.g., Medicaid). Since virtually all basic state health insurance plans include some mental health coverage, it is highly likely that CHIP plans will provide similar coverage. Again, this can vary from state to state, so parents and guardians will have to inquire with the appropriate government agency in the state in which they reside.

In order to obtain further information on CHIP in their state, parents or guardians should contact Medicaid or CHIP officials in their state. Some states have established separate offices for CHIP. A complete state-by-state listing of CHIP and Medicaid offices with phone numbers is available on the Internet at [www.treatment.org/Topics/WHflyer.htm](http://www.treatment.org/Topics/WHflyer.htm).

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## Integrated Method Used at the Center for Cognitive-Behavioral Therapy

The following is an interview with Eda Gorbis, Ph.D., of the Center for Cognitive-Behavioral Therapy and UCLA in Los Angeles, CA. This interview is the second in the series we initiated this summer, describing facilities where OCD sufferers can go for intensive treatment of Obsessive Compulsive Disorder. Dr. Gorbis can be reached at 323.651.1199.



*At the Center for Cognitive-Behavioral Therapy, you use an integrated method for treating OCD. Can you explain the therapies that are included in this system?*

On the Inpatient Unit at UCLA for the treatment of intractable cases of OCD in both children and adults, we use a combination treatment that includes the "Four Steps" developed by Jeffrey Schwartz MD, integrated with a three week intensive treatment protocol developed by Edna Foa, Ph.D., who is now at the University of Pennsylvania Center for the Treatment and Study of Anxiety.

*Do the treatment modalities you use in your Inpatient Program differ from your Outpatient Day Treatment Program?*

Alexander Bystritsky, MD, Ph.D, directs UCLA's Outpatient Day Treatment Program for OCD. In the Day Treatment Program, we don't use Dr. Schwartz' "Four Steps." However, the Inpatient Treatment Program does use the "Four Steps." Our three-week Intensive Program is under the director of Dr. Schwartz. I implement the Intensive Program using the Integrated Method I mentioned above.

*Can you explain the use of Dr. Schwartz' "Four Steps" in your Integrated Method?*

Definitely. The concept of "mindful awareness" plays a central role in how we treat OCD in our Integrated Program. We begin "mindful awareness" training by teaching our patients how to recognize the external and internal triggers that reinforce their obsessions. We spend a great deal of time educating our patients to become aware of "overestimated" threats and "overvalued" situations. Our belief at the Center is that an individual can only begin to control his/her obsessions and compulsions when he or she is fully aware of what, how much and to what extent each trigger bothers him or her.

We feel that this self-monitoring that we teach at the Clinic and in our Intensive Program plays a central part in showing

patients how to Relabel and Reattribute (these are two of Dr. Schwartz' "Steps") overestimated threats. By these means, sufferers can separate themselves from their OCD. In the next step, the staff works with the patient to make a hierarchical order of symptoms and together they design exposure exercises. Then, the patient begins to allow himself to be exposed to the triggers in vivo and through imagery. These repeated exposures lead to the neutralization of fear, which eventually eliminates the need to repeat the rituals. This is how a patient recovers from OCD.

*Does medication treatment play a part in your Integrated Method?*

Yes, medication plays a very important part in our Integrated Method since OCD has co-morbid conditions and each individual case is carefully assessed and referred for a psychopharmacological consultation.

*Do you hospitalize everyone who participates in your Intensive Behavior Treatment Program?*

No. We get a lot of people who are from out of state or out of the country who don't need to be hospitalized, but want an intensive program. Each patient is evaluated in terms of whether he or she should be treated as an inpatient or outpatient. Careful consideration is given to whether or not a particular patient will benefit from the team approach that can be employed on the inpatient ward. However, hospitalization is not right for every patient with OCD. Some of the people in the intensive program stay in nearby hotels where special weekly rates can be arranged.

*Describe your intensive behavior program. How long does it last? What types of therapy does it include?*

Our intensive behavior treatment program includes a total assessment, which consists of a battery of 14 different tests and tools. The program is five days a weeks for three weeks. It focuses on behavior therapy with the emphasis on repeated Exposure and Response Prevention exercises. There is a two-hour group therapy session every week as well as daily two-hour individual sessions in which the therapist and the patient discuss the progress being made and design more E&RP exercises.

*Do you treat patients in your program on a less intensive basis?*

Rarely. For people who can't leave their jobs while getting treatment we have a modified protocol. We have them attend two two-hour sessions weekly. This is

based on a schedule originally designed by Dr. Foa. Of course, every patient can attend our weekly two-hour group session at UCLA.

*Does anyone at the Center use alternative treatments, such as, meditation or herbal medicines?*

At the Center for Cognitive-Behavioral Therapy, we focus mainly on teaching our patients Exposure and Response Prevention. Patients who are specifically interested in "mindful awareness" can schedule a separate consultation with Dr. Schwartz. While our physicians do prescribe medication, no one here uses herbal medicines to treat OCD.

*A big question for our readers is whether most private insurances and/or Medicare or Medicaid cover inpatient and outpatient treatment at the Center?*

A recent California law has defined OCD as a medical illness. The impact of that is that now most insurers and HMOs have to pay for medically necessary treatment for OCD. It's been my experience that our patients usually contact their insurer or HMO directly. If there are any questions, one of the therapists will write a clinical report.

*Is there a protocol at the Center for relapse prevention?*

We have a fourth week, which is called the Relapse Prevention Program. However, we assess each individual patient to decide whether or not he or she would profit from the additional treatment regimen. Of course, people can continue coming to our group for no additional charge for an indefinite period.

*If someone wanted to learn more about your program, what should he or she do?*

Contact me at the Center for Cognitive-Behavioral Therapy  
Intensive Treatment for OCD  
921 Westwood Blvd., Suite 223  
Los Angeles, CA 90024  
Phone: 323.651.1199

I personally talk with each individual who is seriously considering treatment at the Center. I personally assess each case to see if our program would be beneficial. For out-of-state patients, I usually schedule a one-hour telephone appointment for a Saturday so that I can explain the program and do the assessment. For people in the Los Angeles area after an initial consultation with either Dr. Schwartz or me, they can come to our group for an indefinite period at no additional charge.



## BTI's Train 77 New

### Therapists (continued from page 1)

Institutes program and member of its Scientific Advisory Board, as well as director of the Anxiety Disorders Center at St. Louis Behavioral Medicine Institute; Elke Zuercher-White, Ph.D., a member of the Kaiser Permanente's Psychiatry Department; and Patricia Perkins-Doyle, JD, Executive Director of the Foundation.

"We were approached by Dr. Zuercher-White with a request to structure a behavior therapy institute which was affordable and could train up to 90 therapists", explained Perkins-Doyle. "I went to Dr. Pollard with the request and the overlapping BTIs are the result."

"Our goal was to train a large group of therapists without losing the BTIs most unique features: lectures by OCD experts covering all the relevant aspects of treating OCD and the small group treatment planning sessions. In these sessions, attendees work with colleagues and an experienced supervisor to design a CBT treatment plan for their patients," reported Dr. Pollard.

He went on to note: "It took graph paper and a lot of white-out, but we were eventually able to come up with an arrangement that included three overlapping BTIs that cover all the course material and includes one-on-one supervision."

"We kept the entire curriculum," Dr. Pollard stated. "We covered medication and other biological treatments as well as behavior therapy. We included the lectures on diagnosis and assessment, specific applications, treatment of children and adolescents, family impact, comorbidity and practice issues along with the day-long Clinical Rounds."

The therapists who participated were very enthusiastic about the Institute. "The Foundation was really worried that it would not be able to sponsor any more BTIs, revealed Perkins-Doyle. "The BTIs are extremely expensive to stage. There are the honoraria for the faculty, transportation and lodging expenses, rental fees for audiovisual equipment, not to mention printing costs and the administrative time and expense. We found that an affordable tuition price wouldn't cover the costs."

According to Pollard, who is also a professor of Community and Family Medicine at St. Louis University, "cost was a two-edged problem. The Foundation spent more than it could charge to put the BTIs on; and many potential participants couldn't afford the cost of the tuition, plus transportation and lodging on top of losing two days of work."

"It was hectic," said Jonathan Grayson, Ph.D., one of the instructors, but it was worth it. We have 77 new behavior therapists in Northern California. This is going to help a lot of people with OCD."

## Bulletin Board

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### Yale Child Study Center

#### Surveillance Study

At the Yale Child Study Center we are conducting a study which focuses on how certain bacterial infections and life stressors affect tics and obsessive compulsive symptoms in children between 7 and 17 years old. For this study, we will follow about 80 families over the course of 2 years to determine whether symptoms worsen as a result of major life stressors and strep throat infections. Data from this study may lead to new treatment options for individuals who have these conditions. The initial visit entails diagnostic interviews, which survey the child's personality and lifestyle at home and school; blood sampling for DNA analysis and cheek/throat swab; neuropsychological assessments, which evaluate the child's cognitive and motor functioning (i.e., complete puzzle designs); and an MRI scan. Participation entails brief monthly telephone calls to check on the child's current medication and health; periodic blood sampling for DNA analysis and cheek/throat swab, which occur every 4 months; and interviews. The participant receives substantial reimbursement for his or her time and effort: \$85 for the initial visit plus \$60 with an MRI; \$25 each 4 month visit; and up to \$95 should an exacerbation occur.

For more information, please contact:  
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#### Neuroimaging (MRI) Study

At the Yale Child Study Center we are conducting a study which focuses on the differences in brain structure and functioning among individuals with Tourette syndrome (TS), OCD, and attention deficit hyperactivity disorder (ADHD) and unaffected individuals. The protocol includes a MRI scan, neuropsychological assessment and diagnostic interviews. The individual must come for one full day and will receive a \$80 reimbursement. The diagnostic interview surveys the individual's personality and lifestyle at home and school; the neuropsychological assessment evaluates the individual's cognitive functioning and the MRI scan takes 1.5 hours, during which the individual is asked to perform certain tasks (i.e., complete puzzle designs) part of the time.

For more information, please contact:

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#### Prospective Study

At the Yale Child Study Center we are conducting a study in which we follow children who are at genetic risk for OCD and Tourette Syndrome year after year, starting from when they are 3 to 5 years old, over the period of time when they might start having symptoms. Our criteria include: 1 or more children without symptoms who is 3 to 5 years of age, and an older sibling or parent who is affected with TS or OCD or both. We do structured psychiatric interviews on each family member one time and after the first year only do interviews about the child we are following. We have different tests for younger and older children that are age appropriate. We get DNA information sometime over the period that the family is in the study, either drawing blood or taking cheek swabs. In addition, we get information from the child's teacher about how he/she functions in the classroom. There are no benefits to the families in the form of monetary payment, but we do send out a report each year on their child's test results, which may help the parents to know more about their children's strengths and weaknesses, and could lead to further evaluations by the school system if there seems to be a problem.

For more information, please contact:  
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## The Holidays Are Coming!

Shop for all of your end-of-year holiday gifts at **GREATERGOOD.com**. For whatever you need, GO to the OCD website, **HYPERLINK: www.ocfoundation.org**. Click on the OCF SHOPPING PLAZA and shop at the more than 80 retailers listed on the GreaterGood.com Shopping Mall. The OCF has become a partner of GreaterGood.com and will receive up to 15% of the sales price of items bought by shoppers who have registered the OCF Foundation as their charity of choice. This amount is donated by the merchants located at the GreaterGood.com Shopping Mall. So, shop until your fingers won't flex anymore!

**Research – Our Lifeline to a Cure – Support It**



## Interview With A Fund-Raiser



Joy Kant

On Sunday, October 15, Douglas and Joy Kant opened their home in Waban, Massachusetts, to friends and family to hear a talk on OCD by Dr. Michael Jenike.

The invitations called the occasion "A Coffee and Talk." In response to this invitation, the Kants' friends and family contributed over \$29,000 to the OCF Research Fund.

This mellow autumn afternoon gathering was the first research fundraiser put on by Foundation members. We hope that it is not the last. To find out how it was done, Foundation president Janet Emmerman and I went to Boston and interviewed Joy. Emmerman observed: "This event was such a success on both an information-sharing and fund-raising level that we wanted to learn how to do it and to share Joy's secrets with other members who might want to do something similar."

Responding to why she decided to put on the "Coffee and Talk" fundraiser, Joy explained that as a parent of a child diagnosed with OCD, her first thoughts were not about fundraising. "I first tried to find effective treatment for my son. Then I joined the OC Foundation and started receiving the OCD NEWSLETTER. I read it to learn more about OCD and while doing so learned that there was very little money for research. This bothered me. I thought about it and

decided that I personally wanted to do something to increase the money available for research."

Joy thought about different ways of raising money and came up with an idea of doing something in her home. She explained: "I wanted the event to be personal, intimate. I wanted a setting where people could actually have a conversation with a professional about a topic that was personal."



Michael Jenike demonstrating one of the many successful techniques he uses to raise money for research – the headlock.

Once Joy and her husband agreed upon the type of fundraiser they wanted to have, Joy made an appointment at the OCD Institute at McLean Hospital in Belmont, Massachusetts. She met with Diane Baney and Denise Egan, who suggested that Dr. Jenike would be happy to speak about OCD and the research that was being done.

Several months later, Douglas and Joy met with Dr. Jenike to discuss the event. They spent several hours over dinner, talking about OCD, the people affected by the disorder and how little money there was for research.

Jan Emmerman asked Joy about how she decided whom to invite. "I started making a list last winter. It grew as Douglas and I thought about people who had touched our lives both personally and professionally. When my friends heard that we were doing this fundraiser, they called with names of people who might be interested

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Douglas Kant checks his notes before sharing his thoughts with his guests.

## Contributors

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Gerald & Alisa Angowitz  
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Michael Baker  
Stan & Harriet Berman  
Norman & Joci Bernson  
Joseph Biederman  
Gil & Diane Blake  
Rick & Jane Brody  
Richard & Carol Casabonne  
Miceal & Nancie Chamberlain  
Phil & Sarah Clarkson  
Richard & Wendy Cohen  
Joy Collins  
Michael & Anne Connelly  
Jamey Delaplane  
Robert & Dianne Denk  
Elisabeth Ditomassi  
Marjorie Dolan  
Barry Farman & Toby Dondis  
Doug Jones & Virginia Drachman  
Bob & Lynne Dudley  
Bruce Edmands & Geline Edmands  
Herman & Natalie Eisen  
Jan & Herb Emmerman  
Myron & Ann Falchuk  
Curt & Jean Feuer  
Bill Pauker & Shelley Fieland  
Andrew & Patti Fillat  
Robert & Shelley Fish  
Ed & Gretchen Fish  
Doug Fisher  
Barry & Margaret Fogel  
Matt & Julie Forsyth  
Lowell & Paula Fox  
Jerry & Susan Garon  
Harry Garon  
Michael & Carol Ginsberg  
Laura Glynn  
Robert & Jane Glynn  
Lena & Ron Goldberg  
John & Barbara Goodson



# To Research Fundraiser

Peter & Wendy Gordon  
 Jeff & Dale Gordon  
 Jane Haas  
 Neal & Ann Harris  
 Michael & Margery Henzi  
 Stu & Denise Hilger  
 Michael & Stephanie Hoff  
 Maureen Phillips & Douglas Horst  
 Laura Iannetta  
 Jim Ricci & Willemien Insinger  
 David & Anki Javitch  
 Jeffrey & Weiyen Jonas  
 Peter Mebel & Linda Jonash  
 Charlie & Sharon Kamen  
 Douglas & Joy Kant  
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 John & Tappy Kimpel  
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# What Your Research Dollars Are Doing

Dear Foundation Members,

The current status of my OCF-funded research entitled, "Lifetime traumatic experiences and post traumatic stress disorder in patients seeking treatment for obsessive compulsive disorder" is as follows:



*Beth S. Gershuny, Ph.D.*

I am in the process of completing an extensive search of the relevant literature. This will be on-going throughout the project to stay abreast of research developments.

Dr. Sabine Wilhelm and I revised the intake packet given to patients seeking treatment at the OCD Clinic at Massachusetts General Hospital and the OCD Institute to include an assessment of a respondent's lifetime history of trauma and associated systems, e.g., post traumatic stress syndrome. In addition, we developed a questionnaire packet that we give to all of our patients at the Clinic and Institute. The packet contains a variety of OCD-related and trauma-related assessment tools. To date, intake packets and larger questionnaire packets have been distributed to, and returned by, 20 patients.

Data obtained from these packets, along with data previously collected at the Clinic and Institute, as well as data collected at Dr. Edna Foa's Anxiety Center, will be examined later in this project and included during final statistical analysis.

I am looking forward to the continuation of this project throughout the years, and I thank you very much for your financial support.

Sincerely,

Beth S. Gershuny, Ph.D.

**Research - Your Lifeline Support It**



# Research Digest

Selected and abstracted by Bette Hartley, M.L.S. and John H. Greist, M.D.,  
Madison Institute of Medicine [www.miminc.org](http://www.miminc.org)

*The following is a selection of the latest research articles on OCD and related disorders in current scientific journals.*

Gender-related clinical differences in obsessive-compulsive disorder  
European Psychiatry, 14:434-441, 1999, F. Bogetto, S. Venturello, U. Albert et al.

This study investigated the gender-related (sex-related) differences in a sample of 160 patients with OCD. Researchers found three interesting gender-related features of OCD. The first concerns the onset of the disorder: males have an earlier age at onset and precipitant events appear less likely to trigger the disorder. Females more often reported at least one life event or one severe event prior to OCD onset. Childbirth was the most frequently reported event. In 25% of the women versus 2.6% of men, childbirth preceded OCD onset. The second interesting finding is that OCD occurs in a high proportion of males who already have phobias and/or tic disorders. The third finding is that an episodic course (marked by symptom free intervals) of OCD is more frequent in females (35.7%) than in males (13.2%).

A differential neural response in obsessive-compulsive disorder patients with washing – compared with checking – symptoms to disgust  
Psychological Medicine, 30:1037-1050, 2000, M.L. Phillips, I.M. Marks, C. Senior et al.

Patients with OCD have symptoms that predominantly concern washing or checking, or both. This study compared OCD patients who were mainly washers or mainly checkers with normal controls while they viewed pictures of either generally disgusting scenes (rated as disgusting by all subjects) or scenes that particularly disgusted washers. Functional magnetic resonance imaging (brain scans) was used to identify the neural responses. The experience of disgust, in addition to fear and anxiety, when viewing pictures evok-

ing general disgust is associated with activation in visual cortical regions and the insula. Only in washers were similar regions activated by washer relevant pictures. This study provides evidence for a distinction between the two main types of obsessive-compulsive symptoms on the basis of the neural response to visual stimuli.

Hypochondriasis and its relationship to obsessive-compulsive disorder  
Psychiatric Clinics of North America, 23:605-616, 2000, B.A. Fallon, A.I. Qureshi, G. Laje et al.

Hypochondriasis is a disorder characterized by the fear or belief that one has a severe illness based on physical signs or symptoms. Determination by a physician after a thorough evaluation that one is not medically ill fails to result in sustained reassurance...the obsessions with disease return. This article compares hypochondriasis and OCD, and discusses the possibility that hypochondriasis is a subtype of OCD. Response to similar medications supports the concept of hypochondriasis as an OC spectrum disorder, but differing comorbidity patterns (other disorders occurring at the same time) supports the concept of hypochondriasis as a distinct disorder from OCD.

Neuroanatomically based approaches to obsessive-compulsive disorder: neurosurgery and transcranial magnetic stimulation

Psychiatric Clinics of North America, 23:671-686, 2000, B.D. Greenberg, D.L. Murphy and S.A. Rasmussen

Authors review the neurosurgical techniques used in the United States for treatment-resistant OCD. Results of these surgeries show that 40% to 60% of patients with treatment-refractory OCD are considerably improved after neurosurgery. However, the conclusion that neurosurgery benefits patients with intractable OCD must remain tentative, as no controlled trials have been conducted. In contrast to neurosurgery, transcranial

magnetic stimulation (TMS) was developed not as a therapy but as a research tool to study brain activity. In TMS, a pulsing magnetic field created by an electromagnet on the scalp changes the electrical activity in the underlying brain. Repetitive TMS (TMS) has been shown to modify activity in particular brain regions and there is some preliminary indication that TMS may have therapeutic effects in patients with OCD.

An open trial of plasma exchange in childhood-onset obsessive-compulsive disorder without poststreptococcal exacerbations

Journal of the American Academy of Child and Adolescent Psychiatry, 39:1313-1325, 2000, R. Nicolson, S.E. Swedo, M. Lenane et al.

Children with OCD with symptom onset or exacerbations following streptococcal infections have benefited from treatment with plasma exchange, an immunomodulatory therapy. In this study, 5 patients with treatment-refractory OCD without a history of streptococcus-related OCD symptoms underwent an open 2-week course of therapeutic plasma exchange. All 5 patients completed the trial with few side effects, but none showed significant improvement. Researchers state that plasma exchange should be reserved for research studies involving those patients with a clear history of streptococcus-related symptoms.

Personality disorders and traits in patients with body dysmorphic disorder  
Comprehensive Psychiatry, 41:229-236, 2000, K.A. Phillips and S.L. McElroy

A majority of individuals with body dysmorphic disorder (BDD), a preoccupation with a nonexistent or slight defect in appearance, are also diagnosed with personality disorders. Personality disorders were assessed in patients with BDD participating in a fluvoxamine (Luvox) treatment study. Fifty seven percent of these patients with BDD had one or more personality disorders. An interesting finding



is that nearly two thirds of personality disorders were no longer present in patients responding to treatment with fluvoxamine (Luvox). This finding is consistent with similar reports of the disappearance of personality disorders in patients with OCD when the OCD responded to treatment. Ricciardi and others found that 83% of patients with OCD who also met criteria for personality disorders before treatment, no longer met criteria for these disorders after they were effectively treated (Ricciardi JN, Baer L, Jenike MA et al., *Changes in DSM-III-R axis II diagnoses following treatment of obsessive-compulsive disorder*. *Am J Psychiatry*, 149:829-831, 1992).

Treatment histories of patients with three anxiety disorders  
*Depression and Anxiety*, 12:92-98, 2000, K. Rowa, M.M. Anthony, S. Brar et al.

This study examined the extent to which research-supported treatments were used by individuals with panic disorder (n=41), social phobia (n=34) or OCD (n=21). Results indicated that the drug treatments received were more often consistent with research findings than were the psychological treatments received. In the past year efficacious medications were prescribed, either an SSRI (selective serotonin reuptake inhibitor) in 52% of those with OCD or SRI serotonin reuptake inhibitor [clomipramine (Anafranil)] in 33% of those with OCD. In contrast, research evidence supports exposure and ritual prevention for OCD, but only 38% of those with OCD had tried behavior therapy. Results of this study suggest that more work is needed to improve the extent to which patients with anxiety disorders are able to receive evidence-based treatments, particularly cognitive-behavior therapy. Additionally, further research is needed to investigate why there is a discrepancy between the treatments that have been identified as effective and those that are received by patients in clinical practice.

*Article reprints may be obtained from the OC Foundation for \$3.00 per copy for shipping and handling. These articles and additional information on the latest research on OCD and related disorders may also be obtained from the Obsessive Compulsive Information Center, Madison Institute of Medicine, 7617 Mineral Point Road, Suite 300, Madison, WI 53717, (608) 827-2470.*

**DISCLAIMER:** OCF does not endorse any of the medications, treatments, or products reported in this newsletter. This information is intended only to keep you informed. We strongly advise that you check any medications or treatments mentioned with your physician.

## Interview With A Fund-Raiser

(Continued from page 6)

in coming. I made a point of calling these people before I sent them an invitation."

"You sent a letter, too, didn't you?" I asked.

"I did. When I thought about it, I realized that Douglas and I had acquired almost unconsciously a lot of information about OCD. That's what happens when you have to actually live with the illness. Not all the people we were asking would be as well acquainted with OCD."

"Doug and I thought about the contents of the letter a lot," she told me. "We wanted people to know that OCD is very serious and that the available treatments do not cure OCD. So we decided to describe it."

"The invitation," advised Joy, "needed to be sent out well in advance. A friend who has a stationery business made suggestions for the packet. There was an invitation, a response card, a self-addressed, stamped return envelope with directions to our home. I personally wrote the envelopes. I didn't want our friends to think the invitations were machine-generated. Douglas and our daughter, Alexis, made sure that everything got into the envelope (just a little familial OCD)."

"How did you pull together the actual party?" Janet asked. "The food, the drinks, the flowers, the seating." "It took planning and thought," she replied. "I did it by myself because I wanted to, but it would probably be easier for a committee. I used a caterer and a florist who knew my home. The wait staff had been here when my daughter had graduated from high school. I knew that I could depend on them to do a great job and they did just that."

"Doug and I planned the program. He spoke first, welcoming everyone and talked about our son and how kind the doctors have been in treating Jared."

"When it was my turn to introduce the

people from the Foundation, I was overwhelmed. I looked around the room and realized that so many people had come to learn about OCD. I found myself taking the opportunity to thank the people who had been there from the beginning of our journey and for being there with us then," recalled Joy.

"Dr. Jenike spoke with ease and humor. He showed slides to illustrate his talk and answered all the questions that the audience asked. The guests sang his praises for days," Joy reported.

"What advice would you give someone who was thinking of doing a fundraiser?" I asked Joy.

"Put everything on your computer. My son, who is amazing on the computer, made the database, which I used until it crashed the weekend he was away. A friend came to the rescue and was able to retrieve most of it. I must confess that now I make duplicates and send them to my internet account," confided Joy.

"I also suggest you make files for different categories – guest lists, a donation list, weekly donation lists to send to the Foundation, a list of those who have not responded, a list of those who are coming and a list of those who aren't along with lists of thank notes to be written," advised Joy.

"And," Joy added, "here's one little logistical thing: on the day of the fundraiser, have envelopes, a pen and a note saying that the check should be made out to the



Joy, Alexis and Douglas Kant



Guests at the Kants' fundraiser listen to the talk on OCD research given by Dr. Jenike.

OCF Research Fund. One of my guests told me that she was so moved by the event that she went home and made an additional donation."

"The money continues to come in and Doug and I are very grateful for all the kindness and the support that was extended to us during the fundraiser. We will always remember the day, the kind notes and the donations that were earmarked for the OCF Research Fund."



# From the Foundation

Dear Friends,

Among other things, we've started to work on our 8th Annual Conference scheduled for July 20-22, 2001. Actually, what we did was to form a committee of adults and young people with OCD, family members, professionals, industry representatives, members of the board of directors and the OCF staff. Contrary to what Mike Jenike may or may not have said, we did not form this committee just so I won't have to do any work. I wanted to address that slur at the outset.

Although, I must admit that there is some allure to the idea of just showing up as a guest.

The committee met for the first time here in North Branford on November 4. There is another rumor I have to quell before going on – I didn't come to the meeting which was held on a Saturday only because there were Manhattan bagels and cream cheese. I also came because of the sandwiches from the Zach's Deli that are on that nice two-tone bread. But I digress.

While eating the bagels and the sandwiches, we broke into three committees – adults with OCD; children, adolescents and families; and professionals. I was on the Adults with OCD committee. I joined that group because it was located near the kitchenette and allowed me to keep an eye on the sandwich tray. Someone had to do it.

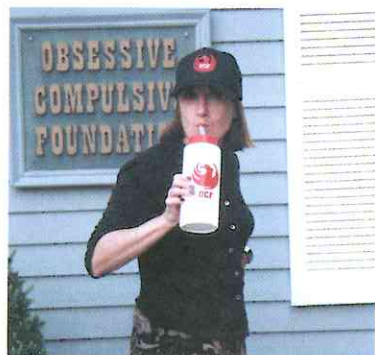
While I was selecting one of every type to taste (to make sure they were all good), I heard my group discussing several panels for next year. They're suggesting a panel that explores all types of CBT from that provided in an in-patient setting to self-taught.

Someone suggested that we should have another Hoarding workshop since I obviously needed help. Let me say here that I only put the sandwiches in the car after I thought everyone had finished.

Several people suggested that we focus on one type of OCD. Others suggested that I stop focusing on the food. The suggestion for this year was Scrupulosity. Alec Pollard proposed that we have individual presentations as we have had in the past, but also have a panel that con-

sists of mental health professionals and religious leaders. Charles Manseuto, Ph.D., who was not on our subcommittee, but who was obviously eavesdropping, felt some irresistible compulsion to say he thought that I should be featured as a Scrupulosity Success Story since I seemed to have no problem taking all of the roast beef sandwiches and (his words) hiding them in my office. As an aside, I would just like to interject that these types of smart aleck comments are what give therapists a bad name.

Another idea that everyone was enthusiastic about was having some sort of orientation for first-time attendees. I suggested that we have food at the orientation. While most agreed that that was for me a pretty good idea, they felt that food



shouldn't be the central focus. They were concerned about introducing newcomers to each other and to get members who had attended before to volunteer to take people under their wings, introduce them around and show them the ropes. I did not think adding the veterans to the equation are a good idea: I can see that they would just be there for the food.

The children and parents subcommittee came up with some really good ideas too. There should be special rooms for kids and teenagers like there were this year where they can do art projects, listen to music, hang out and make s'mores and other treats for the staff to eat. There were suggestions about the kids writing and designing their own Question & Answer brochure in which they could explain OCD to family, friends and teachers. My suggestion, which no one paid any attention to, was that the kids be put to work bringing snacks and cold drinks to the staff. They did pay attention to the idea

that we have more support groups for kids and parents. They also listened when Gayle Frankel talked about getting the kids to write skits or a play that they could put on.

Coming back from getting another Diet Coke, I picked up on a conversation among the three groups. It was about "Success Panels." According to the evaluation forms, participants really liked the Philadelphia Affiliate's presentation, "Recovery: Roadblocks and Shortcuts," because it featured people with OCD talking about how they beat it. The consensus is we should feature success stories. The preliminary suggestion is that we have separate panels featuring adults, kids and Generation Xers who have beat OCD telling their stories.

The professional group, which included several individuals who I won't name who had more than one bagel, proposed an "Ask the Experts" for therapists where attendees could get help from a panel of experts on treatment problems. There was also a suggestion about scheduling an advance BTI on the Thursday afternoon before the Conference began. Following up on this, I suggested that I be treated to a spa day on Thursday. Unfortunately, this subcommittee did not have sufficient vision to see the brilliance of this idea. I think I'm going to need to reconstitute the committee if I'm going to be able to bring my vision into reality.

There was a great deal of talk about OCD and co-morbid conditions. There's been a lot more focus on this lately. The consensus was that we should be encouraging presenters to talk about these from both a diagnostic and treatment point of view.

We talked about "Ask the Experts." We'd like your ideas on how we can refine it. We were thinking about having it on Sunday morning for two hours when there weren't any other presentations so people wouldn't be conflicted and I'd have the breakfast buffet to myself.

This is your conference. We want it to reflect that. So, write me or e-mail me your thoughts and suggestions, especially if they include things like sending chocolates to my room every day and providing me with a Sudan chair from which to direct the action.







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