

OCD and parenting List

The ocdandparenting and parentsofadultchildredwithocd on-line support groups have been instrumental over the years in helping parents and families dealing with OCD. The following is an interview with List-owner Louis Harkins about the support groups.

NEWSLETTER: Would you describe what the ocdandparents and parentsofadultchildrenwithocd on-line support groups are?

HARKINS: The OCD and Parenting List is an online email support group for parents of children with OCD.

The Parents of Adults with OCD List and the OCD and Homeschooling List are "specific focus" extensions of the OCD and Parenting List. Each group exists to establish a community of parents who share information and provide support for one another. The word community here implies a sense of sanctuary and family within which we can all share our experiences and know that we are not alone. This sense of community provides the comfort gained from knowing that there are others who are facing similar challenges and the hope nurtured by the retelling of each step forward that one of our children takes in his struggle to overcome the symptoms of OCD in his life. We learn too from the mistakes that we make and the backward steps that our children take, but even in these negatives we find realization that positive progress is the norm even if there is a backward step for every two steps forward.

NEWSLETTER: How and when did each of these groups start? Whose ideas were they?

HARKINS: I created the OCD and Parenting

List on 23 January 1999 because several parents who were members of the OCD-L (Chris Vertullo's online list for people with OCD) had expressed interest in an online list for parents of children with OCD. I created the Parents of Adults with OCD on 27 August 2000 and the OCD and Homeschooling List on 4 March 2001 because members of the OCD and Parenting List had expressed interest in creation of these lists.

NEWSLETTER: Would you describe what you think are the purposes and goals of the groups?

HARKINS: The purpose of each group is to provide online support of and information for parents of children with OCD. The goal of each group is to establish a sense of community in this process. Each group home page has an extensive listing of links concerning OCD, comorbid disorders related to OCD, mental health, IEP and 504 plans, and parental advocacy issues. Each group home page has a selection of files of specific interest to members of each group. Each group home page has links to a searchable archive of posts to the list. Additionally, each group home page has a link to a chat room where members can chat about mutual concerns.

NEWSLETTER: What kinds of issues and questions are addressed by these groups?

HARKINS: All of our groups discuss issues related to our children and their OCD, but from different perspectives. The OCD and Parenting List primarily deals with OCD in younger children through their

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A Letter from the President

Dear Members,

First, on behalf of the Board of Directors, I want you all to know that our thoughts are with those of you, your friends and family members who have been affected by the horrific events that occurred on September 11. We wish you and our country peace in the coming months.

Earlier this month, on September 8, I had the privilege of attending the Diller Street Theatre in Winnetka, Illinois, a suburb just north of Chicago. That evening along with 300 other theatergoers, I



saw a performance of a new play entitled, "OC Me." The play was written and directed by a uniquely talented and bright young woman, Jessica Honor Carlton. "Jessie," as her friends call her, also plays the lead character. In this role, she played a high school student with drive, charm and heart who had recently experienced a sudden and rapid onset of OCD.

While the play's story is fiction, the author has drawn upon her own experiences of dealing with OCD as a teenager, the family's struggle and the

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From the Foundation

Dear Friends,

First, the staff of the OCF sends its deepest sympathy to the families, friends and colleagues of the victims of the events of September 11.

Many things are happening here. As I write this, Leah Davis, an OCF member from Cumberland, MD, is working on the Obsessive Compulsive Disorder Benefit Golf Tournament scheduled for September 24, 2001. Leah has single-handedly organized this outing. There's the actual tournament, contests and prizes, and a dinner. Supporters at the following treatment facilities and affiliates have contributed to the benefit as "Flag Sponsors":

The OCD Institute at McLean Hospital, Belmont, MA

OCF Affiliate of Greater Boston

Anxiety Treatment Center of Northern California, Sacramento, CA

Center for the Treatment of Obsessive Compulsive Disorder, Western Psychiatric Institute and Clinic, Pittsburgh, PA

Behavior Therapy Center of Greater Washington, Silver Spring, MD

Bio-Behavioral Institute, Great Neck, NY

The Menninger Clinic, Topeka, KS

The Anxiety & Agoraphobia Treatment Center, Bala Cynwyd, PA

Cognitive Behavioral Institute for OCD and Anxiety Disorders, Los Angeles, CA

The Obsessive-Compulsive Disorder Center at Rogers Memorial Hospital, Oconomowoc, WI

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BULLETIN BOARD

COLUMBIA UNIVERSITY STUDY FOR PATIENTS WITH PERSISTENT OCD DESPITE TREATMENT

The Columbia University IV Clomipramine study in northern New York City is in its final few months of patient enrollment. Enrollment will stop as of March 1, 2002. If you continue to suffer from OCD despite having received adequate treatment with at least two different typical medications for OCD, then please contact Drs. Fallon and Feinstein about the NIH-funded IV Clomipramine study. Patients between age 18 and 60 can be treated free of charge on an inpatient or an outpatient basis. Patients are required to come to Columbia for the 2 weeks of IV therapy, after which all patients are given oral clomipramine for 8 weeks to see if responders have additional improvement. Financial assistance will be provided toward travel expenses. Please contact Dr. Feinstein at 212-543-5132 to discuss the study details.

NATIONAL INSTITUTE OF MENTAL HEALTH INTRAMURAL RESEARCH PROGRAM

Obsessive-Compulsive Spectrum Studies

The National Institute of Mental Health is seeking adults who suffer from:

- Obsessive-Compulsive Disorder
- Hoarding or excessive collecting
- Trichotillomania (compulsive hair pulling)
- Tourette's Disorder

to participate in studies at the NIH Clinical Center in Bethesda, Maryland. You may be eligible for:

- Free evaluation
- Personality Study (compensation offered)
- Family and Genetics Study (compensation offered)
- Upcoming brain functioning and imaging studies

Obsessions or compulsions related to the following symptoms are not eligible: Compulsive sexual behavior, eating, shopping, gambling, or substance use.

For more information contact: John Gause at 301-496-3421 or email jgause@codon.nih.gov

THE ANXIETY DISORDERS CLINIC NEW YORK PRESBYTERIAN HOSPITAL

Do you suffer from Obsessive-Compulsive Disorder and live within commuting distance of New York City?

Are you on medication but still have symptoms?

You may be eligible to participate in a research study that would provide cognitive-behavioral therapy and medication at no cost to you.

Please call for more information.

The Anxiety Disorders Clinic
New York Presbyterian Hospital
New York State Psychiatric Institute/RFMH
(212) 543-5367
(IRB#3697)

STUDY ON OCD AND THE SEROTONIN TRANSPORTER GENE

Everybody has a serotonin transporter gene, and for a given individual, the gene has either two long alleles ("arms"), two short alleles, or one long and one short allele. For people with short alleles, the serotonin system may not work optimally. Non-optimal functioning of the serotonin system has been implicated in several disorders, including OCD.

Our project will assess the association between OC symptoms and having short alleles on the serotonin transporter gene. All participants will have the inside of their cheeks swabbed with a Q-tip like brush – cells from the inside of the cheek are caught in the brush. Then we extract DNA from the cells, from which we can determine the allelic structure of the serotonin transporter gene. All participants will also be assessed for OC-spectrum disorder symptoms.

Residents of Tallahassee, Florida, and surrounding regions are eligible to take part in the project. Participants will be paid \$10 upon completion of the study.

For information, please contact the project coordinator, Marisol Perez, Florida State University. Phone: (850) 644-9362 or e-mail: perez@psy.fsu.edu. The principal investigator for this project is Dr. Thomas Joiner.

COGNITIVE-BEHAVIORAL THERAPY TRIAL FOR PEOPLE WHO HAVE NOT BEEN HELPED BY MEDICATION

The Anxiety Disorders Center at The Institute of Living/Hartford Hospital's Mental Health Network is conducting a study of people with Obsessive-Compulsive Disorder (OCD) who have not been helped by medications or have only been helped minimally by medications. Participants will receive free cognitive-behavioral therapy, one of the most effective treatments for OCD.

The study is open to adults aged 18-65 who have Obsessive-Compulsive Disorder, who are not currently receiving psychotherapy, and who have tried at least two medications without receiving maximum benefit.

If you are interested in participating in this study, please contact Dr. David Tolin, Director of the Anxiety Disorders Center at (860) 545-7685 or at dtolin@harthosp.org

OCF's Harvest Tag Sale & Fundraiser

October 20, 8 am - 3 pm

To contribute items, call Hillary at (203) 315-2190 or email: macko@ocfoundation.org



OCD NEWSLETTER

The OCD Newsletter is published six times a year.

Obsessive Compulsive Foundation, Inc.

Phone: (203) 315-2190

Fax: (203) 315-2196

e-mail: info@ocfoundation.org

www.ocfoundation.org

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The Obsessive-Compulsive Foundation (OCF) is an international not-for-profit advocacy organization with more than 10,000 members worldwide. Its 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.

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.

UCLA Offers Intensive Program for Obsessive-Compulsive Disorder

Gerald Tarlow, Ph.D., director of Psychological Services at the Obsessive-Compulsive Disorder Intensive Treatment Program at UCLA, answered the OCD NEWSLETTER'S questions about this "partial" intensive treatment program for OCD sufferers with moderate to severe OCD.

NEWSLETTER: UCLA has a program called the Obsessive-Compulsive Disorder Intensive Treatment Program. Can you describe it for our readers?

TARLOW: The UCLA OCD Program is an intensive treatment program for people suffering with moderate to severe levels of the disorder. Intensive treatment involves up to three hours daily of behavior therapy in the form of exposure and response prevention and exposure in imagination. It is a 6 week program that operates Monday- Friday, from 9-1 p.m.

NEWSLETTER: What treatment modalities are used in this program?

TARLOW: The primary treatment modality is individual behavior therapy. The patients also attend an OCD specific group each day and receive medication management while in the program.

NEWSLETTER: As a standard practice do you offer behavior therapy and medication?

TARLOW: Yes. Most of our patients receive both behavior therapy and medication due to the severity of their symptoms. However, we will consider the use of behavior therapy alone depending on the individual case.

NEWSLETTER: What forms of behavior therapy are utilized in your program?

TARLOW: We utilize exposure and response prevention and exposure in imagination techniques. We generally emphasize gradual exposure with most patients.

NEWSLETTER: UCLA's program is a "partial" program. Can you explain what that means by contrasting it with a full time program or typical non-intensive treatment? Why would someone choose it over an inpatient program?

TARLOW: The UCLA program meets for four hours per day, five days per week. Patients then either go home or go to a local hotel. Residential and inpatient programs are 24 hours per day, seven days per week. We feel that allowing patients to go home at the conclusion of the program day gives them practice in the environment that they will be spending time once they leave the program. Many people need to practice exposures in their own home or with people in their environment that often triggers their obsessions. Our program is also less expensive than inpatient treatment and most residential treatment.

NEWSLETTER: What are the treatment goals of your program? In other words, at the end of your standard program, where should a patient be? Ready to go back to work or school? Ready for less intensive treatment?

TARLOW: Our goals are to significantly reduce the level of severity of a patient's obsessions and compulsions to the point that s/he would be able to function effectively in school, work and interpersonal relationships. The patient should be able to return to individual outpatient behavior therapy on a one or two time per week frequency.

NEWSLETTER: How long has this UCLA program been in existence?

TARLOW: The program was started in June 1990. It was one of the first treatment programs of its kind.

NEWSLETTER: Describe a typical day for a patient in this program.

TARLOW: Each patient is assigned their own behavior therapist with whom he or she works individually throughout the program. During the first hour of the day the patient meets with his/her therapist individually to review the behavioral assignments from the previous day and to plan assignments for the present day. The patient then does approximately one hour of behavioral assignments under the supervision of the staff. Next, the patient attends a one-hour group that focuses on a different aspect of OCD treatment each day. Finally, the patient spends the last hour of the day doing another behavioral assignment. Very often patients do an in-vivo exposure in the morning and an imaginal exposure in the afternoon.

NEWSLETTER: At what type of patient is this program aimed? Those with moderate impairment? Severe impairment?

TARLOW: Generally, the program is aimed at patients with moderate to severe OCD that prevents them from being able to function at work and at school. OCD often interferes with the patient's interpersonal functioning.

NEWSLETTER: Do you have any data on the success rate of people going through your program?

TARLOW: We have extensive data on the results of our program. Ninety-six percent of our patients reduce the severity of their OCD symptoms by at least 25% within the six weeks of the program. Fifty percent of our

patients achieve at least a 50% reduction. The overall average reduction in severity of symptoms is 48%. We have shown that these gains have been maintained for at least two years after discharge from the program.

NEWSLETTER: Your standard program is six weeks in length. What contingencies are there if a patient is still severely disabled at the end of the standard program?

TARLOW: We are somewhat flexible. If a patient needs a few extra days, or even weeks, it may be possible to extend the stay. However, what we usually do if someone needs a lot more time is to discharge them from the program at the end of six weeks with assignments

to help him/her maintain the gains s/he has made. We will then admit this patient back to the program when s/he has had a break for a few months. We find that the six-week program is very tiring and there are times people need to take a break and practice what they have learned before they return to continue treatment.



Clinical staff at the UCLA Partial Program

NEWSLETTER: Do you have an intensive inpatient program?

TARLOW: Currently we do not offer an inpatient program. We have plans to start an inpatient component of the OCD program within the next year.

NEWSLETTER: Do you have an after-care program?

TARLOW: We make sure that each patient has adequate behavior therapy and medication follow-up treatment planned prior to leaving our program. We often refer patients to local OCD support groups as part of their follow-up.

NEWSLETTER: How does the program address the relapse issue?

TARLOW: Relapse Prevention is an issue that is addressed from the start of treatment. All the patients attend a relapse prevention group one day per week while they are in the program. We also communicate with the behavior therapist and the psychiatrist that the patient will see upon discharge. Outcome data from the program shows that patients do a lot better when they follow up with outpatient treatment upon discharge from the program.

NEWSLETTER: Does the program have access to temporary housing for patients who don't live within commuting distance of the center?

How We Found the Right Help for Our Son, Alexandre

By Robert Van Gent
Vancouver, British Columbia, Canada

After two traumatic incidents last summer, our son, Alexandre started to "hear voices." Later, we found out that they weren't voices, they were thoughts, actually obsessions. Before he could go to sleep, he had to get out of bed and go through a ritual involving putting his clothes and toys in a certain order. At other times, he had to "report" certain "bad words" that he had heard. Every morning, he had to make his bed "perfectly" before he could do anything else. Then he began and couldn't stop flipping light switches on and off until it felt just right. He did this at night until he woke the whole house. And, he started to wash his hands over and over again.

All this started slowly and we thought that it was just part of "growing up." It seemed like it was just a phase because most of these rituals disappeared. Unfortunately, as we were to learn, they were replaced with new ones, such as, having to walk back and forth, cleaning his feet meticulously before he could put his pants and shoes on and symmetrically licking his left and right upper arms. We didn't know what was happening.

Then, late last February while driving I was listening to a talk show on my car radio. The host and guest were talking about someone doing the same kinds of things Alexandre had been doing. They said that these activities were symptoms of a neurobiological disease called Obsessive Compulsive Disorder. It hit me: this is what Alexandre has. I pulled off the road to write it down, Obsessive Compulsive Disorder. I didn't want to forget the name.

That weekend, my wife and I were scheduled to start a weeklong trip to Mexico. Alexandre didn't want us to go. We assured him everything would be all right. His older brother was coming to stay with him. He'd take good care of him. When his brother got there, I told him about what had been happening with Alexandre since the summer before. For the first time, I used the words, "Obsessive Compulsive Disorder," to describe what was happening.

We were gone a day, when we received a call from Alexandre's brother. First, Alexandre had gotten a cold, then he ran a fever and through it all his OCD got worse. The rituals were running rampant

and he couldn't sleep. We flew back home immediately. Our return reassured him somewhat and Alexandre seemed to get much better. He seemed to go back to his old self. In the meantime, our older son went on the Internet, looking for information about OCD. He found a lot, including a booklist and an organization, the OCFoundation.

We were hungry for information about OCD. We got Tamar Chansky's book, "Freeing Your Child From Obsessive Compulsive Disorder." It helped us tremendously. During our Easter vacation, we called the OCFoundation and talked with Patricia Perkins-Doyle. She warned me NOT to go to just any doctor, but to find one who specialized in treating OCD. She gave us the names of several doctors and therapists. My wife and I discussed it and we contacted both Dr. Robert King at the Yale Child Study Center in New Haven, CT and the Anxiety Disorders Clinic at the Saint Louis Behavioral Medicine Institute in St. Louis, MO.

We wanted to take him to Yale for a full diagnosis and consultation. Unfortunately, the first appointment we could get there was in May and that was getting bumped ahead on the waiting list where the first appointment was July. We really wanted a workup and consultation with experts who specialized in children.

But the OCD escalated heedless of waiting lists and flight schedules. Finally, Alexandre had a really bad day in school. He could not stop ritually licking his upper arms. It made him feel so badly he did not want to go back to school. That was a Friday. We decided over the weekend that we couldn't wait any longer to get him help.

On Monday morning, I called Heidi Pollard at the St. Louis Behavioral Medicine Institute and asked her to help Alexandre and us as soon as possible. We knew that Alexandre needed behavior therapy and needed it NOW. We decided that the consultation and full workup could wait, but Alexandre had to have some relief immediately.

As Heidi explained to us later, they made room for us immediately because Alexandre had not been seen by a therapist or doctor up until that time. Alexandre was ready and willing to fight the OCD with all that he had and he hated his rituals. Gary Mitchell, a therapist at the Institute, realized the time was now. He carved out time

from his life so he could help Alexandre. That afternoon, we were on a plane from British Columbia to St. Louis. The staff did an initial assessment and Alexandre started behavior therapy the next day.

Working with Alexandre and me, Gary designed a two-week behavior treatment plan where Alexandre worked with a therapist for two hours every morning and he and I worked together in the afternoon.

After three days, we started to see results. First, he stopped licking his upper arms. By the end of the next two weeks, he was able to stop another five rituals and, most importantly, both of us felt confident that from now on we had a handle on the OCD and any of the rituals it might throw at us in the future. Through the immediate and professional help from the staff at Saint Louis Behavioral Medicine Institute, we were able to help Alexandre live a better life.

As I write this more than a month after returning from St. Louis, Alexandre still has some rituals that we have to work on daily, but we got some very good advice from Dr. King at the consultation we had in New Haven on May 14 that is working. Our success shows that the suggestion we got from the OCFoundation to find the right doctor and the right therapist was the key to save Alexandre from OCD.



Tax Tips: Charitable Gifts of Stock

By Kathleen Bornhorst, JD
Wealth Preservation Practice Group
Pepe & Hazard
Hartford, CT

Consider a Charitable Gift of Stock

Publicly traded securities are the most common form of a noncash charitable gift. Stock makes an attractive gift because it is often highly appreciated and it is easily transferred. As long as the donor has held the stock for one year and the stock qualifies as long-term capital gain property, the value of the stock can be deducted for charitable income tax deduction purposes at its fair market value. The resulting deduction is subject to the 30% limitation, i.e., the donor may deduct charitable contributions in an amount up to 30% of his adjusted gross income. Any unused charitable deduction may be carried over for five years. For example, Chris donates shares of XYZ stock, purchased more than one year before the gift for \$100, to the OC Foundation. As of the date of gift, XYZ stock is valued at \$500. Chris has a charitable deduction of \$500.

If the donor has not held stock for at least a year, the contribution of stock to a charity is treated as ordinary income property and the charitable deduction is based on the lower of the donor's adjusted cost basis, or fair market value on the date of contribution. The resulting deduction is subject to the 50% deduction limitation, i.e., the donor may deduct charitable contributions in an amount up to 50% of his adjusted gross income. Any unused deduction may be carried over for five years. For example, Carter wishes to make a gift of \$1,000 to the OC Foundation. Carter sells shares of ABC stock that he purchased for \$2,000, for \$1,000. Carter has a short-term capital loss of \$1,000 and after giving the \$1,000 to the OC Foundation, a charitable deduction of \$1,000.

In order to determine the fair market value of publicly-traded stock and then calculate the charitable deduction, one must calculate the mean between the highest and lowest quoted selling prices on the valuation date. The date of delivery of securities to the charitable beneficiary determines the date that the gift is valued. This is particularly critical to end-of-the-year contributions if one finds that the gift was delivered, and therefore deemed to be made in the following tax year. The date on which the delivery of securities is considered complete depends on whom the securities are deliv-

ered by, and to whom they are delivered.

If the donor or the donor's broker physically delivers securities to the charity, the transfer is considered complete on the date the endorsed certificate is delivered.

If properly endorsed securities are mailed to the charity or broker by the donor's broker, delivery is considered complete on the date of mailing, provided the charity receives it in the ordinary course of the mail.

If the donor delivers a stock certificate to his broker or to the issuing corporation for transfer into the name of the charity, the gift is complete on the date the stock is transferred on the books of the corporation.

If securities are held in brokerage accounts in a street name, the donor must instruct her broker to transfer the securities from her account into the account of the charity. The delivery date is the date on which the brokerage firm transfers title. In this situation it is important to note that a transfer is not made at the time the instructions to transfer are given to the broker, rather it is the date on which the transfer is made on the books of the issuing corporation. A donor considering a year-end transfer must make sure that there is adequate time for this transfer to occur. Otherwise, the donor runs the risk the transfer will actually be completed in the following tax year.

Mutual Funds

Mutual funds make an attractive charitable gift candidate. A fair market value of a share in an open end investment company (mutual fund) is the public redemption price of a share. If there is no public redemption price quoted by the company for the date of gift, the fair market value of the mutual fund share is the last public redemption price quoted by the company for the first day before the date of gift for which there is a quotation.

Closed-End Investment Companies

A closed-end investment company, unlike a mutual fund, does not continuously offer to buy back its shares at the option of its shareholders, nor does it continuously offer to sell its shares. After an initial sale by the company, the shares are traded in the secondary market like the shares of any other public corporation. Shares in a closed-end investment company trade in a manner similar to stock and are therefore valued in the same manner.

Real Estate Investment Trusts

Real estate investment trusts (REIT) may make a suitable gift to a charitable entity if the REIT does not produce unrelated business taxable income or if it is not prohibited from being owned by a charitable organization. The prospectus of the REIT should provide this information.

Master Limited Partnerships

Master Limited Partnerships may not be a suitable contribution asset to a charitable entity. Master Limited Partnerships should be considered only after a thorough examination of the partnership prospectus and with specific attention given to possible unrelated business income.

Other Opportunities

Attractive giving opportunities are also available for donors who wish to make a gift of stock options and restricted stock. The opportunities available for charities and most importantly, donors to use planned giving tools such as a charitable remainder trust, charitable lead trust or direct gift to charities as part of succession planning and tax reduction for those options and restricted stock are immense.

If you want additional information about charitable gifts of stock, contact the Executive Director of the Foundation, and remember, when planning a major gift to a charity, it is important to consult your tax advisor well in advance of the gift.

OCF's Harvest Tag Sale & Fundraiser

October 20, 8 am - 3 pm

Harvest Tag Sale - where someone else's trash is another's treasure! An exciting array of items including everything from A to Z to raise money for OCD education and awareness in schools.

Please join us for this worthy event to raise funds for OCD Education!

The OCF Harvest Tag Sale will be held at the OCF National Headquarters located at the intersection of Rte. 80 & Rte. 22 on 337 Notch Hill Road in North Branford, CT. Guaranteed...something for everyone!

House wares, Furniture, Home Decor, Crafts, Clothes, Costumes, Food & Fun!

OCD and Parenting

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teen years with emphasis on helping them learn to live with and overcome OCD with the help of adequate medication, cognitive behavioral therapy, and exposure and response prevention.

Many of the posts to this list deal with schooling issues (IEP's, 504 Plans, etc.), socialization problems, medication changes, developmental issues, and the relationship issues that tend to be triggered by the presence of OCD in the family setting.

The Parents of Adults with OCD List primarily deals with OCD in adult children. These parents have generally lived with OCD longer than the members of the OCD and Parenting List. Many of us did not have the increasing wealth of information that is now available to parents when a child is diagnosed with OCD. Our children deal with issues not yet faced by the younger children represented on the OCD and Parenting List. Issues include acceptance of OCD diagnosis, willingness to take medications, educational opportunities, encouragement of independence, finding and keeping jobs, Social Security disability, availability of housing for our disabled children, etc.

The OCD and Homeschooling List exists to enable members to discuss the unique variety of homeschooling options that are available to parents of children with OCD who decide to educate their children at home.

NEWSLETTER: Do these groups have "real time meetings" or do visitors go on-line at any time and pose a question or make a comment and just wait for an answer?

HARKINS: Members of each of the lists currently meet on the chat feature of the OCD and Parenting List every Sunday night at 2200 hours EST. This meeting occurs in real time and provides a written exchange of ideas between members who participate. Participating in our chat feature is much like a written conversation and gives members a chance to know each other in a more conversational context. Our chat feature offers the capability for audio communication and we may experiment with that in the future as well.

NEWSLETTER: You "own" the ocdandparenting list. What does that mean?

HARKINS: Ownership of these email lists primarily entails maintenance of the membership's subscription options, creation of links and files for the lists, and oversight of list traffic with emphasis on topicality of posts to the list. I have transferred ownership of the Parents of Adults with OCD List to Jackie Stout, but I still maintain links, files, and subscription options for that list. I still serve as list owner for the OCD and Parenting List and the OCD and Homeschooling List. Ownership is a position of service to the members of the list.

NEWSLETTER: The lists have "moderators." Who are they and what do they do?

HARKINS: The OCD and Parenting List has eight moderators. They are Wendy Birkhan, Kathy Hammes, Cindy Joye, Jule Monnens,

Gail Pesses, Kathy Robinson, Vivian Stembridge, and Jackie Stout. I asked each of these women to become moderators because of the quality and quantity of their participation in our list community. The moderators answer questions asked by other members based on their experience in dealing with OCD in their own family context. Our moderators are women who have read extensively about OCD and who have participated in the annual OCF conferences. Their commitment to helping other parents of children with OCD is described by the number of questions they answer and by the many posts expressing gratitude for those answers from our members. The participation of our moderators essentially defines what list moderation is.

The Parents of Adults with OCD List has five moderators. They are Wendy Birkhan, Kathy Hammes, Kathy Robinson, Vivian Stembridge, and myself. Jackie Stout serves as owner of this list.

I serve as owner and moderator of the OCD and Homeschooling List. As time passes and membership grows I intend to recruit moderators for this list as well.

NEWSLETTER: Who are typical members of the Lists? What motivates someone to become involved with the List group?

HARKINS: Typical new members of the OCD and Parenting List are parents who have recently received a diagnosis of OCD in one or more of their children. They are like I was when my older son, Louis, was diagnosed at age twelve in 1994. They are concerned about the symptoms and devastating effects of the disorder that has finally been given a name: OCD. They feel isolated because they do not know any other families with children who have OCD and they need support in the form of understanding and information from other parents who have experienced the same disappointment, frustration, doubts, and heartaches that they are experiencing. Essentially our motivation to join is the desire for information and to communicate with other parents who have children with OCD. Most of our members stay because of the richness of the communal experience and their desire to reach out and help others as they have been helped. So much of the family dynamic is invested in this struggle to help our children with OCD that we must learn to take care of ourselves, our marriages, and our children without OCD as well.

A typical new member of the Parents of Adults with OCD has been living with OCD symptoms in one or more children for years and has recently discovered our list as a resource for information and support.

They also stay because of our sense of community and a desire to help others who join in the future. Many of the members of the OCD and Parenting List will, one day, graduate to the Parents of Adults with OCD List.

A typical new member of the OCD and Homeschooling List is a parent of one or more children with OCD.

Our members have decided to educate their child or children at home. Many of us home-

school out of necessity and others would have chosen homeschooling even if their child or children did not have OCD.

Those who homeschool out of necessity are normally doing so because they could not obtain cooperation from their local school systems.

Those who would have chosen to homeschool even if their child or children did not have OCD are normally doing so because of the enriching family experience that homeschooling can be.

NEWSLETTER: What are the topics that are usually addressed in the chat groups?

HARKINS: The chat meetings normally discuss day-to-day experiences of the parents who are participating. We also discuss specific problems that are raised during the course of the conversation. Many issues are raised at the same time and the discourse runs from one topic to another, but the net gain is that we share experiences and get to know each other in a deeper, more human way – person-to-person. Topics range from medications, cognitive behavioral therapy, exposure and response prevention, learning not to be an "enabling parent", school issues, family issues, and often personal issues that are more easily expressed in the conversational format of chat as opposed to email communication.

NEWSLETTER: How can someone become involved in the groups? Do you have to "join" in some way or can you just "drop in" and ask questions or make comments?

HARKINS: Each of the groups must be joined by emailing a subscription address. I have included the subscription addresses:

- (1) OCDandParenting-subscribe@yahoogroups.com
- (2) ParentsofadultswithOCD-subscribe@yahoogroups.com
- (3) OCDandHomeschooling-subscribe@yahoogroups.com

NEWSLETTER: Do you have to pay a fee or dues to participate in the groups?

HARKINS: There are no fees or dues for participation in our online email support groups.

NEWSLETTER: What are the groups' email addresses?

HARKINS: I have included the subscription addresses in a previous answer, but I would like to give you my personal email addresses, lharkins@bellsouth.net, louisharkins@hotmail.com, or louisharkins@yahoo.com. If anyone experiences subscription difficulties I shall be happy to assist them in the subscription process.

NEWSLETTER: Are there any rules or guidelines that participants are asked to follow?

HARKINS: There are no formal rules; however, we expect mutual respect and kindness from each other. There are no formal guidelines except for our insistence on remaining topical, i.e., all posts must be related directly to the name of the particular list involved, i.e., OCD and parenting, parenting an adult with OCD, or

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UCLA INTERVIEW

(continued from page 3)

TARLOW: Many patients stay in local hotels or motels that are in easy walking distance of UCLA. We can supply a list of local hotels to help people coming from out of the area.

NEWSLETTER: Who is on your staff and what are their backgrounds?

TARLOW: I am the Director of Psychological Services at the program. I am also an Associate Clinical Professor in the Department of Psychiatry at UCLA and have over 25 years experience in treating anxiety disorders. Alexander Bystritsky, M.D., is the Medical Director. He is a Clinical Professor in the Department of Psychiatry and has been the Director of the UCLA Anxiety Disorders Program for the past fifteen years. He has published over 120 papers and has been listed in the Best Doctors in America for the past seven years. Karron Maidment RN, M.A. is the program coordinator and also one of the therapists in the program. The rest of the program staff consists of the behavior therapists. They come from all different disciplines; nursing, psychology and social work. This is advantageous since every discipline brings its own unique qualities to the overall treatment of the patients. However, all the behavior therapists are equally qualified in the area of behavior therapy for the treatment of OCD.

NEWSLETTER: Is group therapy a component of your program?

TARLOW: Yes. The patients attend one hour of group therapy per day. The five groups are: 1) Program Planning – identifying behavioral goals for the week and brainstorming reasons for successes and failures from the previous week. 2) OCD Didactic – learning about the definition of OCD, how to recognize it, causes of OCD, and effective treatment of OCD. 3) Relapse Prevention – recognizing triggers for relapse, implementing strategies to prevent further relapse, stress management and support systems. 4) Family Dynamics – discusses common family issues that occur when someone has OCD and 5) Cognitive Therapy – recognizing and addressing common thought distortions that feed into OCD.

NEWSLETTER: At our annual conference several presenters discuss the role of the family in the treatment of OCD. Does your program involve family members or the patient's support network in the treatment? How significant is this involvement in getting and sustaining recovery?

TARLOW: We always try to involve family members with the permission of the patient. We often have family sessions while the patient is in the program to provide educa-

tion and support. The family's involvement is often extremely important in terms of the ability of the patient to generalize what was learned in the program to his/her home environment. The family also needs to learn how to most effectively help the OCD person without enabling the OCD.

NEWSLETTER: What kinds of follow-up is involved?

TARLOW: The importance of outpatient follow up for our patients is stressed throughout their stay, both by their doctor, their therapist and in the groups. Every patient should have an outpatient therapist and a psychiatrist when s/he leaves the program. We find that the first six months after a patient leaves our program is a vulnerable time for him/her and outpatient behavior therapy follow-up is essential to reduce risk of relapse. We also refer patients to local OCD support groups. Every six months we contact patients who have completed the program and reassess their OCD and level of functioning.

NEWSLETTER: Does an OCD sufferer have to be referred to your program by a mental health professional?

TARLOW: Patients can be referred by their therapist or self-referred. All potential patients need to be evaluated by Dr. Tarlow prior to coming into the program. He can be reached at (310) 208-4077 to set up an appointment for an evaluation. Once evaluated a patient will be put on a waiting list and as soon as an opening is available he will be contacted with a start date. Patients are usually given 1-2 weeks notice of a start date.

NEWSLETTER: Is the program covered by most private insurance carriers and HMOs? What about Medicare and Medicaid, will they cover this intensive treatment program?

TARLOW: Most private insurance carriers and Medicare cover a substantial percentage of the cost of the program.

NEWSLETTER: Are there any scholarships or subsidies available for individuals who are not insured or whose insurance doesn't cover your program?

TARLOW: At this time we do not have any scholarships or subsidies available for patients.

NEWSLETTER: What kinds of patients will get the most out of your program? Those that are severely disabled? Moderately disabled?

TARLOW: The level of disability is not as important as the level of the patient's motivation to get better. Any highly motivated patient, who puts the time and the effort into our treatment program, will get better.

NEWSLETTER: Does your staff also treat individuals with OCD Spectrum Disorders, such as, body dysmorphic disorder, trichotillomania, and hypochondriasis?

TARLOW: We often treat OCD spectrum disorders. BDD and skin picking are the two most common spectrum disorders that we

treat.

NEWSLETTER: Are any of your staff involved in OCD research? Are there any studies that a person with OCD could become involved with?

TARLOW: We have a number of studies. We are doing a five-year naturalistic follow-up study on patients who have participated in the Intensive Treatment Program. We call patients who were in the program every year and do a battery of rating scales to see how they compare to when they started the program and when they left. We look at severity of OCD, depression and anxiety. We also look at a person's general quality of life to see if it improves as OCD symptoms get better.

Our brain imaging study is a twelve-week study that involves having a PET scan of the brain before and after twelve weeks of treatment with Paxil (Paroxetine). The study also involves having an MRI of the brain. The study is designed so that we can look at changes in the brain metabolism before and after treatment. Currently, we are especially looking for people with the hoarding type of OCD for this study. Patients who participate in this study may also undergo a battery of neurocognitive tests that can later be mapped against the results of their PET scan. They also give a small sample of blood for genetic testing. Anyone interested in this study can call Karron Maidment at (310) 794-7305.

Our child and adolescent OCD Program also offers a number of studies. They have a behavior therapy study, a Prozac study, and genetic and neuroimmunology studies. For more information on the child and adolescent programs and research protocols, one should call (310) 825-0122.

NEWSLETTER: Can patients with co-morbid conditions participate in the program? What about someone who also has a substance abuse problem?

TARLOW: Many patients have a co-morbid condition. We generally require that the OCD be the primary diagnosis. If a co-morbid condition would interfere with treatment we would generally prefer the patient be treated for the co-morbid condition prior to entering our program. If a patient has a substance abuse problem we require that he be in some form of treatment for the substance abuse concurrently with treatment in our program.

NEWSLETTER: If someone is interested in learning more about your program, who should he contact?

TARLOW: Patients should contact Karron Maidment RN, M.A, the program coordinator at (310) 794-7305.

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United Way Charity*

Research Digest

Selected and abstracted by Bette Hartley, M.L.S., and John H. Greist, M.D., Madison Institute of Medicine

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

Oral morphine in treatment resistant obsessive-compulsive disorder (OCD)
Presented at the New Clinical Drug Evaluation Unit Program, Phoenix, AZ, May 28-31, 2001, Session II-38, L.M. Koran, B. Franz, Bullock K.D. et al.

Results from a placebo and lorazepam-controlled, double-blind study, using once weekly oral morphine to treat 8 individuals with treatment-resistant OCD are reported. This was a short-term 2 week study, with lorazepam (Ativan) as a control medication so individuals would be less likely to know if they were receiving morphine. A decrease in OCD symptoms occurred with morphine, including 3 individuals with Yale-Brown Obsessive Compulsive Scale scores decreasing more than 40%, whereas lorazepam and placebo were ineffective. Since morphine is given only weekly, the mechanism of its effect must be different than when used for pain relief. Weekly dosing also diminishes the risk of addiction. Morphine may prove beneficial for some individuals with highly treatment-resistant OCD.

Dr. Greist: I have cared for a patient with OCD for over 20 years who had not responded well to any medication treatments but currently obtains some relief with morphine.

Right prefrontal repetitive transcranial magnetic stimulation in obsessive-compulsive disorder: a double-blind, placebo-controlled study
American Journal of Psychiatry, 158:1143-1145, 2001, P. Alonso, J. Pujol, N. Cardoner et al.

A 1997 study with 12 patients, by Dr. Greenberg and others, found modest effects of transcranial magnetic stimulation (rTMS) on compulsions and no effect on obsessions. This second investigation of the value of rTMS treatment of OCD used a double-blind method with a sham (pretend) treatment as a control. Patients were randomly assigned to 18 sessions of real rTMS or sham rTMS, three sessions per week for 6 weeks. No significant changes in

OCD were detected in either group after treatment. Despite negative results, the researchers suggest further studies to clarify if rTMS could be a useful therapy in OCD.

The concealment of obsessions
Behaviour Research and Therapy, 39:457-464, 2001, S. Newth and S. Rachman

Patients typically conceal from others the content and frequency of their obsessions. Drs. Newth and Rachman discuss the significance of this concealment as part of their cognitive theory of obsessions. They encourage disclosures in their treatment program. Revealing obsessions to the therapist is the first step. Commonly, individuals begin with obsessions that are not too shameful or describe the obsessions in vague terms. Slowly they develop the confidence to describe their obsessions in detail. Talking about obsessions can be a stressful experience and for some individuals causes a physical reaction similar to a panic attack, with increased breathing and other symptoms. Often the patient is also encouraged to make disclosures to a limited number of carefully selected people. With patient consent, it is helpful to provide the individual receiving the disclosure with information about OCD and the nature of obsessional thoughts. Talking about obsessions may be therapeutic as it involves a process of desensitization by gradual exposure. In addition to the relief the individual feels in revealing the obsessions, the individual also begins to acquire new information and interpretations from others that can be useful in modifying the catastrophic significance that is attached to the obsession.

Fluoxetine in pathologic skin-picking: open-label and double-blind results
Psychosomatics, 42:314-319, 2001, M.R. Bloch, M. Elliott, H. Thompson et al.

Pathologic skin picking refers to excessive picking to the point of causing skin damage and possible disfigurement. It has been viewed as an obsessive-compulsive spectrum disorder and often accompanies body dysmorphic disorder. Previous studies have shown compulsive skin picking responds to treatment with selective sero-

tonin reuptake inhibitors (SSRIs), specifically fluoxetine (Prozac), sertraline (Zoloft) and fluvoxamine (Luvox). This study further investigates the effectiveness of fluoxetine and found 50% of the patients responded to 6 weeks of treatment (20 mg/day to 60 mg/day). Additionally, symptoms returned for those responders who discontinued medication.

Prevalence and clinical features of body dysmorphic disorder in adolescent and adult psychiatric inpatients
Journal of Clinical Psychiatry, 62:517-522, 2001, J.E. Grant, S.W. Kim and S.J. Crow

Body dysmorphic disorder (BDD), a preoccupation with an imagined or slight defect in appearance, is an under-recognized psychiatric disorder. This study looked at the incidence of BDD in 122 individuals seeking inpatient psychiatric treatment at a university hospital. Previously undiagnosed during their hospitalization, 13.1% of these patients were diagnosed with BDD. Depression and substance abuse disorder were the primary reason for hospitalization. Due to feelings of shame, these patients reported that they would not tell their physician about their concerns unless specifically asked. They kept their concerns secret from their clinicians, even though when interviewed they reported their BDD symptoms to be the "biggest" problem they had. The patients suffering with BDD also had a more clinically severe illness than patients without BDD, including almost twice as many suicide attempts as those without BDD. Researchers conclude that BDD may be relatively common in the psychiatric inpatient setting and it is important that physicians ask specifically about BDD because, as this study shows, patients will not voluntarily raise these concerns.

Pediatric autoimmune neuropsychiatric disorders associated with streptococcal infection (PANDAS)
International Journal of Neuropsychopharmacology, 4:191-198, 2001, H.L. Leonard and S.E. Swedo

PANDAS is defined by five characteristics: (1) presence of OCD and/or a tic disorder; (2) childhood onset; (3) episodic course; (4) association between symptoms and strepto-

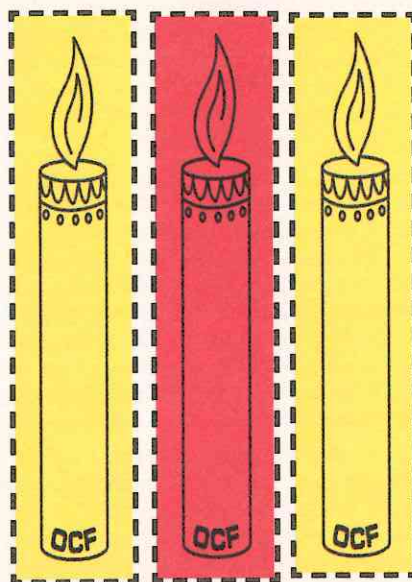
coccal infections and (5) associated neurological abnormalities. Leading researchers provide a current update on this topic, including their recommendations for treatment. The OCD symptoms occurring in children in the PANDAS subgroup are similar to OCD symptoms occurring in children not in this subgroup. One characteristic which differentiates the PANDAS subgroup is the sudden, dramatic onset of the OCD. Also the PANDAS subgroup is distinguished by the very early age at onset of symptoms. Therapeutic plasma exchange (TPE) and administration of intravenous immunoglobulins (IVIG) are two treatments showing promise in treating PANDAS. Because both these treatments are invasive and associated with risks, these experts recommend that they be reserved for severely ill children with clear evidence of PANDAS. Children with mild to moderate symptoms should not undergo TPE or IVIG therapy. Children without evidence of immune-mediated symptoms from streptococcal infections should not be treated with these therapies, as they are unlikely to be helpful and carry a risk of adverse effects. Lengthy antibiotic use with penicillin has been investigated as a treatment for PANDAS and failed to lessen the OCD or tics. Appropriate antibiotic treatment for streptococcal infections is suggested but not long term antibiotic treatment.

Quality of life and disability in patients with obsessive-compulsive disorder
European Psychiatry, 16:239-245, 2001, J. Bobes, M.P. Gonzalez, M.T. Bascaran et al.

Comparisons of quality of life and disability are made between Spanish OCD patients and U.S. OCD patients, as well as comparisons between OCD patients and patients with schizophrenia, heroin addiction, depression and kidney failure. A disabling disorder, OCD interferes with social and family functioning, impairs work and school functioning, and, in general, negatively affects quality of life. Consistent with other research, patients in this study were often disabled by their OCD, the greatest level of disability being in social and occupational areas. Additionally, the physicians' disability ratings found OCD to be as disabling as schizophrenia and more disabling than the other disorders with which it was being compared. The OCD patients reported similar quality of life as individuals with schizophrenia, but a worse quality of life than individuals with heroin addiction or depression. In comparison to individuals with kidney failure on hemodialysis, OCD patients were found to function at an equal or higher level in the areas of physical health but lower levels in areas of mental health. Also of interest, the social functioning of these Spanish OCD patients was rated as more impaired than that of U.S. OCD patients.

Long-term outcome and prognosis of obsessive-compulsive disorder with onset in childhood or adolescence
European Child & Adolescent Psychiatry, 10:37-46, 2001, C. Wewetzer, T. Jans, B. Muller et al.

OCD in children and adolescents is more common than once recognized, with prevalence rates varying between 1% and 4% in studies. In this study, with an average follow-up of 11 years, researchers reevaluated 55 patients with early onset OCD to determine their long-term outcome. At follow-up only 36% were still suffering from OCD, but 71% were suffering from a psychiatric disorder. Also more than one third of patients were diagnosed with a personality disorder at follow-up, including a higher incidence of obsessive-compulsive personality disorder than has been found in other studies. There was a continuing course of OCD in many patients with a high incidence of psychiatric disorders in the long-term follow-up. Most of the patients had not received behavior therapy or medication treatment with selective serotonin reuptake inhibitors during the follow-up period. Hopefully with these treatments there will be a better long-term outcome of childhood OCD in the future.



November 1, 2001 will be the 15th birthday of the OC Foundation. Help us celebrate by buying a candle for our cake. Candles are \$2 a piece; three for \$5.00. Cut out the candles on this page (xerox them to make more) and send them to the Foundation. The money we raise from our birthday celebration is going to fund the Education Task Force. This group is reviewing and revising the video set "How to Recognize and Respond to OCD in the Classroom" and developing a program to train parents to put on this presentation in their local schools. Buy a candle and help our kids. That's the best way to celebrate our birthday.

OCD and Parenting

(continued from page 6)

OCD and homeschooling.

NEWSLETTER: Confidentiality is a big issue for most people involved with OCD. How do your groups handle this concern?

HARKINS: Each of our lists is a private list that can be joined by anyone. Only members may post to the list and only members may read posts from the list. The archive, file, and link features for each list may be accessed by members only. We each share as much of ourselves as we wish to reveal within this envelope of limited privacy. Each of us shares of ourself for the benefit of the others and this mutual revelation of experience comprises much of what our list is about. It is this willingness to step out from the shadow of OCD and communicate that illuminates our minds and brings the warmth of communal endeavor.

NEWSLETTER: Are any therapists or psychiatrists involved in the Lists? Who and in what capacities? Do they give advice? Answer questions?

HARKINS: Currently only the OCD and Parenting List includes participation by professionals in the mental health field. I am looking for professionals to participate in both the Parents of Adults with OCD List and the OCD and Homeschooling List.

The OCD and Parenting List is blessed by the participation of Tamar Chansky, Ph.D., Aureen Pinto Wagner, Ph.D., and Dan Geller, MD. Dr. Chansky is the author of "Freeing Your Child from Obsessive-Compulsive Disorder". Her book is now available in paperback edition at <http://www.amazon.com>.

Dr. Wagner is the author of "Up and Down The Worry Hill". She is currently writing "Helping Anxious Children and Adolescents in School: A Parent-Educator Partnership", to be published in the fall of 2001, and "What To Do When Your Child Has OCD", to be published in early 2002. Her books are available through her publisher at <http://www.lighthouse-press.com>.

Dan Geller, M.D., is the Director of the Pediatric OCD Clinic at the McLean Hospital of the Harvard Medical School.

Each of our professionals answers questions in an "Ask the Expert" format. Also, both Tamar Chansky and Aureen Wagner participate by posting to the list on topics that are responsive to current issues being discussed by members and about general themes that are relevant to parenting a child with OCD.

NEWSLETTER: Finally, whom would you advise to "log on" to these groups?

HARKINS: I would advise any parent of a child with OCD to join one or more of these groups. Also, I welcome participation by any mental health professionals who are willing to help either in an "Ask the Expert" format or by posting to any of the lists on general topics of interest to parents of children with OCD. Anyone desiring information about any of the parenting lists may contact me at one of my email addresses.

From the Foundation

(continued from page 1)

OCD Resource Center of South Florida,
Hollywood, FL

The Anxiety Disorder Center at The
Institute Of Living, Hartford, CT

Stress & Anxiety Disorders Clinic,
University of Illinois School of Medicine

Obsessive-Compulsive Disorder Intensive
Treatment Program at UCLA, Los Angeles,
CA

Some people from the OCF staff and board of directors are going to play in the Tournament. I'll be manning the OCF booth and giving out literature. Suffice it to say, I have a restriction on my driver's license that includes golf carts and spherical objects. When you read this, the tournament will have been played and the word spread around central Maryland about OCD.



OCF Gothic

In the Midwest, Robert and Nancy Guenther, Foundation members from Illinois, have organized a "Coffee and Dessert and a Talk with Dr. David Pauls" for Sunday, October 14 at 2:30 pm. Dr. Pauls, who along with his new position as director of the Unit of Psychiatric and Neurobehavioral Genetics at Massachusetts General Hospital/Harvard Medical School, is putting together the OCF Genetics Consortium, will speak about his ongoing genetics research.

In the letter the Guenther's sent out with the invitations to "The Coffee" fundraiser, they talked about the impact that neurobiological disorders have had on their own family and the importance of genetic research in furthering the OCF's goal of "Effective Treatments for Everyone with OCD."

The money raised by this event, which will take place at the Devonshire Cultural Center in Skokie, IL, is going toward the OCF Genetics Consortium. Anyone interested in attending the "Coffee and Dessert" can contact Nancy Guenther at (847) 675-3632.

Back in North Branford, we've filled our reception area with gently used items for

our "Harvest Festival and Hoarders Tag Sale," which is scheduled for Saturday, October 20, in the parking lot we share with the Dental Office next store. The OCF staff is presently occupying itself with calling friends and family begging for "good



Sara Kish pricing merchandise gathered for the Harvest Festival & Hoarders' Tag Sale.

stuff" to sell at the Tag Sale. We're visiting the local merchants asking for donations of snacks, pumpkins, and harvest goods. Hillary's painted a sandwich board sign that she wanted Jeannette to wear at the local Outlet mall. There was a discussion (not really, as heated as was reported by the local press) and the sign is standing on its own on Route 22. Its twin, which is slated for Route 80, is under production.

Our intern, Michelle (who just started her freshman year at Southern Connecticut State College) asked her Psychology professor if she could ask her class for donations and volunteers. Now her class is filling up this professor's office with gently used things. We were able to clear up the misunderstanding with the other faculty members who thought they were seeing a gifts-for-grades scheme.

We've called the local press and they've promised not only to run an announcement for the sale, but are going to do an article on it and the Foundation. They're coming over next week to do an interview and take photographs. We've asked for 24-hour notice so we can straighten up our offices and get our hair done.

If you're in the neighborhood (anywhere from White Plains, NY to Springfield, MA) and have items to donate or want to volunteer, please call Hillary at 203.315.2190, Ext. 5. We need taggers and sorters. Think of it as behavior therapy.

If you or your group is interested in doing a "Hoarders Tag Sale," call Hillary. She'll share will you what she's learned about putting one on.

Besides trying to foster a sense of commu-

nity and educate our neighbors and friends about OCD through our "Harvest Festival and Hoarders Tag Sale," we're putting on this event to raise money to support the work of our Education Task Force. The goal of this group, which is drawn from OCF members nationwide, is to provide programs for educators about how OCD affects a child's behavior in the classroom and ability to study and learn and how as teachers they can respond and help.

The group had its first face-to-face meeting at the Annual Conference in Denver. They are now working on updating and revising the video program, "How to Recognize and Respond to OCD in the Classroom," designing a presentation format so parents can take this programs to their schools and setting up a distribution plan to get this information into teachers' hands. All of this costs money. We raised a little more than \$800 at the Conference selling birthday candles and cake. Members have been cutting out the candles from the last issue of the NEWSLETTER and sending them in with donations for the Education Task Force. But we've got a way to go before we have sufficient resources to be able to afford to carry out our plans. Think how far we could spread the word with the proceeds from multiple "Hoarders Tag Sales."



The Tag Sale Salesforce

This one's still on the drawing board. Gail Frankel, co-president of the Philadelphia OCD affiliate, and Jan Emmerman, president of the OCF Board of Directors, are our idea people. What we want to do and what we would like OCD Support Groups around the country do is "A Wrapping Night" at your local Barnes & Noble. The "Wrapping Night" would take place shortly before Christmas. B&N allows local groups to sign up for a specific date. On that date, volunteers from that group are available in the store to wrap gifts for shoppers. The group gets to keep the tips paid by the

patrons for the wrapping. Some stores will even allow a group to have the own "Shopping Night." The group gets their friends, families and colleagues to shop at that store that night and get a percentage of the profits.

The OCF can organize "Wrapping Nights" across the country by working with Barnes & Noble's corporate staff. If your group is interested, call me and let me know. If enough people want to do it, we'll take this plan off the drawing board and bring it into reality.

We're also working on the 2002 Research Awards program. Dr. Lorrin Koran, professor of Psychiatry and Director of the Stanford OCD Clinic, has agreed to chair the subcommittee of the OCF Scientific Advisory Board that reviews all grant applications and recommends the projects to be funded to the OCF Board of Directors. The Call for Proposals will be issued in mid October. We have not setup a deadline for submissions yet.

The decision's been made on the 9th Annual OCF Conference. It's going to be in Philadelphia, From August 9-11. It's going to be at the Wyndham Hotel. We'll be asking for Presentation Proposals later this year. If there is topic you want to see explored or an issue you want to address, let us know. The program is a blank canvas now. Let us know how you want us to fill it.

Finally, we are continuing to try to connect parents and their children with OCD with skilled treaters. This is one of the most important things we do. At least once a day, we hear from a family that has not been able to find effective treatment for their son or daughter. If you specialize in treating children with OCD and aren't on our Referral Lists, please call and sign up. If you have found some who had done a good job treating your child, let us know about him or her. Or, tell him or her about us and urge them to get on our Referral List. Help us get effective treatment for every child with OCD.

We're also updating our pamphlets, slowly and one at a time. Our printer just delivered 10,000 copies of Dr. Michael A. Jenike's "Drug Treatment of OCD in Adults: A Guide". You can order it by contacting Daisy Sanchez at the Foundation. Barbara Van Noppen is making the last revisions on the fifth edition of "Learning to Live with OCD." We're hoping the printer can have this ready for us before the end of the year. And, we're listening. We want to hear from you about what you need and what you want.

Ciao!



Patricia Perkins-Doyle
Executive Director

From the President

(continued from page 1)

problems of fitting in, as well as trying to be an excellent student with a successful social life. The caliber of Jessica's writing coupled with her perception and sensitivity set her and this play apart from the other 188 young playwrights who had entered the Playwright Discovery Award competition. Jessica won third place in this competition that challenges young people to write plays that have to do with disabilities. She will be receiving her award at the Kennedy Center in Washington in October.

I was personally moved emotionally by this play, as was the rest of the audience, because at its core, it is a retelling of the universal story of the triumph of the human spirit over adversity. But beyond that, however, was the realization by everyone in the audience who had been affected by OCD either personally or through loved ones, that the play was important on other levels as well.

For the OCD community, Jessica has produced a serious artistic portrayal of a person with OCD. She did the writing, the recruitment of professional and amateur actors who volunteered their time, and directed the play throughout the summer while her classmates were enjoying a leisurely vacation before starting college, all the while dealing with OCD herself. With the play's award Jessica has received validation from beyond the OCD community and her friends at our Chicago affiliate. It is also important because the play focuses attention on OCD, its possible treatments, and the people that it affects. Perhaps, most importantly, as Jessica states in the play's Program, "This is not a story about OCD, it is a story of a person. When a person has a disability – they are a person first. Part of the reason I wrote this play was to try and dispel some of the stigma which surrounds issues of mental illness."

While there have been other forms of expression in the arts in recent years about OCD and related disorders, we are all enriched because a 17-year old young woman has had the courage and the talent to tell a story that is so close to her heart. And, we in the OCD community are enriched because she has told our story so well.

Jessica started at Northwestern University this September. This serves as a reminder to us all that communicating with our children's teachers and school psychologists about OCD is critical to their ultimate success.

We can make a difference! It highlights the importance of the work of our newly formed Education Task Force, a group made up of volunteers that include par-



ents, educators, physicians, psychologists and even students. We must get the appropriate information to every school and to every teacher through informational programs for educational professionals.

We must also continue to encourage and support research that focuses upon OCD's effects upon learning and cognition. This year the Foundation gave a research award to Cary R. Savage, Ph.D., for his project, "Developing a Cognitive Rehabilitation Program for OCD." In the article in the Late Spring edition of this NEWSLETTER, announcing the award to Dr. Savage, Lee Baer, Ph.D., chair of the 2001 Research Awards subcommittee for our Scientific Advisory, commented: "This innovative study will attempt to develop a rehabilitation treatment to help individuals with OCD to surmount memory problems that appear to be part of their OCD."

We now know from other research that OCD can affect how people study and learn. We still need to discover exactly how this occurs and how to develop techniques to compensate for these problems and ultimately eliminate them.

As I thought about "OC Me," it became clear that we must continue our work to educate our educators about OCD, and that we also must continue to encourage and support research that pinpoints the effects of OCD and discover a variety of means to overcome its ill effects upon concentration, studying and learning. We must learn how to overcome this disability and allow peoples' talent and brilliance to shine-just like Jessica did.

Janet Emmerman
President,
OCF Board of Directors

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the
Education
Task
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