TLC-Funded Research: Overview of New and Current Projects

Compiled by TLC Staff

The cornerstone of TLC’s research efforts is our Annual Grant program. Thanks to Member support over the last decade, we have made grants of between $10,000 - $20,000 to support seed projects that will further our understanding and/or treatment of trichotillomania, skin picking disorder and related Body-Focused Repetitive Behaviors. Though these grants are relatively small, they are designed to support studies that will have large ripple effects, laying the groundwork for larger federal or private funding and nurturing promising researchers in this field.

TLC grants have supported efforts to better understand the phenomenology of hair pulling and skin picking; to investigate the neurology and genetics of these disorders; and to develop new treatment options from Acceptance and Commitment Therapy to computerized cognitive training to N-acetylcysteine.

Our goal was to double the size of this program by 2013. I am delighted to announce that thanks to your support and a generous donation by Art and Amy Buckman, we have reached that goal a year early and will be funding two important studies this year:

2012 Grant Award Recipients

1. Translational Study of Cognition in Adults with Trichotillomania and Unaffected First-Degree Relatives using Functional Neuroimaging

Brian L. Odlaug, MPH
PhD Candidate, Research
University of Minnesota, Dept. of Psychiatry
Ambulatory Research Center
Samuel R. Chamberlain, MD, PhD
Senior Visiting Clinical Research Research Fellow
Department of Psychiatry
University of Cambridge

TLC is pleased to award Mr. Brian Odlaug (University of Chicago) and Dr. Samuel Chamberlain (Cambridge University) a TLC Research Grant to study cognitive testing during brain imaging (known as functional imaging) in an effort to better understand the state versus trait nature of neurobiological changes in trichotillomania. There is an ongoing search in psychiatry for models of the neurobiological circuitry implicated in given disorders. Whether or not trichotillomania is associated with subtle changes in brain function (as opposed to structure) is not yet established and although functional imaging has been used, with considerable success, to identify biological markers in other impulsive-compulsive disorders (such as Obsessive Compulsive Disorder), there is a paucity of functional imaging studies in trichotillomania.

Furthermore, no studies to date have examined brain activation in unaffected first-degree relatives of individuals with trichotillomania – a vital first step in the detection of trait biological markers that may shed important light on the genetic underpinnings of such behaviors. Understanding whether differences in brain functioning exist between individuals with TTM, first-degree relatives and a sample of healthy controls may aid in the development of new treatments for trichotillomania and other body-focused repetitive behaviors such as skin picking disorder.

The hypothesis to be tested is that trichotillomania subjects and unaffected first-degree relatives of trichotillomania subjects will show under-activation of brain regions during cognitive tests when compared to controls with no known family history of the condition. The study will examine a total of 36 individuals: twelve

Continued on page 12

Updates from TLC Research Partners

Compiled by TLC Staff

Current Research in the Behavior Therapy and Research Lab

University of Wisconsin - Milwaukee

Doug Woods, PhD
Department of Psychology
Behavior Therapy and Research Lab

The Behavior Therapy and Research Lab at the University of Wisconsin-Milwaukee specializes in conducting research on understanding and treating repetitive behavior disorders, including hair pulling disorder (HPD; trichotillomania), skin picking disorder (SPD), and other body focused repetitive behaviors (BFRBs). Much of the research in the Lab is done in our Trichotillomania/BFRB Specialty Clinic. We have a number of different projects in our lab. Generally, they focus on three areas; treatment, understanding the social impact of the problems, and research that better our understanding of how TTM/BFRBs should be classified.

Treatment

An important goal of the lab is to develop and test behavioral interventions for individuals with HPD, SPD and other BFRBs. Currently, we are conducting a large randomized control trial funded by The National Institute of Mental Health (NIMH). In this trial, we are comparing the efficacy of acceptance-enhanced behavioral therapy (AEBT) to a psychoeducation and supportive therapy intervention in the treatment for HPD. We have reason to believe that both treatments may benefit hair pulling sufferers, but this is the first time that these interventions are examined in a large randomized controlled trial. Participation involves 10 psychotherapy sessions as well as several assessment sessions before, during and after treatment. The treatment is free, and participants are paid up to $200 for their involvement in the study. As of now, we have recruited several participants, and are looking to continue recruitment through 2013.

Continued on page 10
The Trichotillomania Learning Center’s mission is to end the suffering caused by hair pulling disorder, skin picking disorder, and related body-focused repetitive behaviors. We envision a world where:

- Body-focused Repetitive Behaviors (BFRBs) are not a source of shame.
- Knowledgeable treatment is available to all people with these disorders.
- Treatments are more effective and eventually cures are found.
- Information and emotional support are available to people of all ages and their families.

Our Tax ID number is: 77-0266587.
TLC is a 501(c)(3) tax-exempt organization and all funds to support TLC’s work (and, incidentally, the work of the researchers mentioned in this newsletter).

On the more experiential side of things, I hope you will consider joining us in our neck of the woods as the Annual Retreat returns home to Pema Osel Ling Retreat Center in the Santa Cruz Mountains. Now in its 21st year, the Retreat is like summer camp without any of the social peer groups, where you arrive as strangers and leave best friends.

I shared this quote with you last year, and I still like it a lot, so I’m printing it again. From TLC Retreatant, Chris, in 2010: I went to the retreat last year and it was fantastic! I did not know anyone there before I went. Everyone was SO NICE. The information was fantastic. It was a Very Supportive event and I would recommend it to ANYONE. Even if you are not good with strangers or crowds (as I am not), you will have a blast. I had never met anyone with trich before (to my knowledge) and that was a good feeling to meet others. Please go- you won’t regret it!

Well said!
So we’ll see you all this fall.

xoxo ~Leslie

Christina with her “kids” at the 2011 Retreat. Photo by Doug Schwartz Photography.

The Trichotillomania Learning Center
207 McPherson Street, Suite H
Santa Cruz, California 95060
(831) 457-1004
www.trich.org
info@trich.org
Editor: Leslie Lee

We are especially grateful to Fred for believing in the integral need for rigorous scientific research and having the willingness to fund it, and for continuing to make the dream of a cure a reality, all in the service of love.

—Christina Pearson
TLC Founder

“The LARGEST PRIVATELY FUNDED RESEARCH STUDY EVER CONDUCTED IN THE FIELD OF TRICHTOILLOMANIA

The Trichotillomania Family Study: Part 1: The Role of Environmental Variables
Part 2: Comorbidity of TTM and Related Disorders in First-Degree Biological Relatives

Investigators:
Nancy Keuthen, PhD, Amanda Allen, BS, Anna Raff, BS, Erin Altenburger, BS, Elizabeth Loerke, BS, Jeanne Fama, PhD & David Pauls, PhD

The Trichotillomania Family Study sought to answer the following questions:

- Is the family environment perceived differently by adolescent pullers vs. controls?
- Is the family environment perceived differently by parents of adolescent pullers vs. parents of controls?
- Is perception of the family environment by adolescent probands correlated with hair pulling severity?

Preliminary results of this study were presented at the 2012 TLC Conference by Principal Investigators Drs. Nancy Keuthen and David Pauls, of Massachusetts General Hospital, Harvard Medical School. As the data is still under analysis and pending publication, we cannot report on the results directly, but would like to use this space to thank Fred Bartlett for his vision and dedication to the BFRB community, to the researchers for their guidance and insight in seeing this project through, and to the 100+ families who traveled from all over the US to take part in this study.

“If we are going to get better answers we need to support serious research. That is why I put my donations where my heart is and have given over $1 million to support ground-breaking trichotillomania research. These gifts funded the pilot phase of TLC’s Trichotillomania International Research Consortium, and the “Family Study” at Massachusetts General Hospital Harvard Medical School. I hope these donations will inspire others to get behind research efforts so we can move the field forward!”

—Fred J. Bartlett
Former Chaplain,
17-year member of TLC
Kansas City, MO

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From the Editor
Leslie Lee

Welcome to the 4th Annual Research Edition of the TLC Newsletter!

Coming off the conference just a few weeks ago, which showcased the largest number of research presentations thus far, we can’t help but be excited about the volume and quality of research currently underway in the BFRB field. The dedication that these researchers embody for this community is inspiring. They do this work because they care, because at some point in their careers they were touched by the impact hair pulling and skin picking have on the lives of those affected, from kids to adult men and women, parents and spouses. It was truly inspiring to witness the mix of patients, parents, spouses, and siblings mingling, brainstorming, and even problem-solving with the brilliant members of TLC’s Scientific Advisory Board and their colleagues.

July also marks the start of preparations for National Trichotillomania and Skin Picking Awareness Week. On page 6, you’ll find information on participating in the annual Hands-Down-a-Thon, as well as a new program coordinated by Christina, Trekking for Trich and Skin Picking. These two programs allow ANYONE to get involved in raising awareness and funds to support TLC’s work (and, incidentally, the work of the researchers mentioned in this newsletter).

On the more experiential side of things, I hope you will consider joining us in our neck of the woods as the Annual Retreat returns home to Pema Osel Ling Retreat Center in the Santa Cruz Mountains. Now in its 21st year, the Retreat is like summer camp without any of the social peer groups, where you arrive as strangers and leave best friends.

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Well said!
So we’ll see you all this fall.

xoxo ~Leslie

Christina with her “kids” at the 2011 Retreat. Photo by Doug Schwartz Photography.
Research Participation Opportunities

Tampa/St. Petersburg, Florida
Habit Reversal Training for Children and Adolescents with Trichotillomania: A Controlled Trial
Researchers at the University of South Florida in Tampa/St. Petersburg, Florida, are currently investigating how well a treatment called Habit Reversal Training (HRT) works to help children and teenagers with Trichotillomania manage and reduce their hair pulling. All children who qualify for the study will receive eight sessions of HRT. The study also involves four visits to the clinic where you and your child will participate in study assessments. These assessments will involve answering questions about your child’s hair pulling and other psychological symptoms.
To be in the study, your child must:
• Be between the ages of 7 and 17 years
• Have significant hair pulling
• Not have any health problems that could interfere with study participation
There is no cost for participating. For more information, please contact the study coordinator, Erika Crawford, at the Rothman Center for Neuropsychiatry at the University of South Florida at (727) 767-8230.

Boston, MA
Massachusetts General Hospital- Trichotillomania Clinic
Dr. Nancy Keuthen is conducting a genetics research study of compulsive hair pulling at Massachusetts General Hospital. You may be eligible if you are 18-65 years of age and frequently pull out your hair. If eligible for this research study, you will come to the Center for the Treatment and Study of Anxiety in Philadelphia. Participants will receive either Behavior Therapy or Supportive Counseling. Children and adolescents, ages 10 through 17, who repetitively pull their hair may be eligible to participate in this study. Must live in the greater Philadelphia area to participate. For more information on this program, contact: Kristin Benavides: 215-746-3327, or kben@mail.med.upenn.edu.

Milwaukee, WI
University of Wisconsin-Milwaukee Treatment Studies
For Adolescents: Computerized Cognitive Training Programs for Trichotillomania
The Psychology Department at the UWM is conducting research on the effectiveness of computer-based treatment programs for compulsive hair pulling in children. The study will take up to 2 months to complete, treatment is free, and participants will be paid up to $110 for their participation in the study. For more information, please contact: Hanjo Lee, PhD, Assistant Professor, Department of Psychology, University of Wisconsin-Milwaukee: (414) 228-5858 or TrichStudy@gmail.com.

For Parents of Children aged 5-9
Is your child between the ages of 5 and 9? If so, you and your child may be eligible for a research study involving a non-drug treatment and would take up to 9 weeks to complete. Treatment is provided free of cost. For more information, call: Chris Bauer (414) 229-2830.

For Adults: Acceptance-Enhanced Behavior Therapy for TTM
Are you an adult between the ages of 18 and 65 who pulls your hair? The Psychology Department at the UWM is conducting research on the effectiveness of non-drug treatments for hair pulling in adults. The study will take up to 9 months to complete, treatment is free, and participants will be paid up to $500 for their participation in the study. For more information, please call: Chris Bauer, Study Coordinator, Department of Psychology, UWM: (414) 229-2830.

Kent, OH
Children with Hair Pulling Disorder Needed for Family Assessment Study
Does your child pull out his/her hair? Does this pulling cause a problem at school, with friends, or at home? The Child Anxurety Research (CARE) Program is looking for youths who pull out their hair and teenagers, and one of their parents to participate in a research study. Those eligible receive a full assessment of symptoms, compensation, and written feedback including potential diagnosis, treatment options and referrals. Please call 672-2200 if interested. **Not all families will qualify. Duration of participation for these families will not exceed 2 hours. This posting has been approved by the Kent State University Institutional Review Board.

Philadelphia, PA
Child/Adolescent OCD, Tics, Trichotillomania and Anxiety Group (COTTAGe)
Martin Franklin, PhD, is examining treatments for children at the Center for the Treatment and Study of Anxiety in Philadelphia. Participants will receive either Behavior Therapy or Supportive Counseling. Children and adolescents, ages 10 through 17, who repetitively pull their hair may be eligible to participate in this study. Must live in the greater Philadelphia area to participate. For more information on this program, contact: Kristin Benavides: 215-746-3327, or kben@mail.med.upenn.edu.

TLC national events

One-Day Workshop: Minneapolis
September 27, 2012
Join Christina Pearson and Jon Grant, JD, MD, MPH, for an incredible opportunity to delve into the multi-faceted issues of hair pulling and skin picking disorders.
Christina will share her strategies for maintaining years of recovery from hair pulling and skin picking. Dr. Grant, who is known for his charismatic presentations and ability to translate scientific information to consumers, will provide an overview of medications, dietary supplements such as N-Acetylcysteine (NAC), and how these pharmacological methods blend with other therapeutic treatments for BFRBs.
Attendees will develop new insight into WHY it can be so difficult to alter these behaviors, and learn about emerging understanding of more effective ways to live with, and heal from, these problems. Patients, parents, support persons and professionals are invited to attend. Visit www.trich.org for registration and a program schedule.

National Hair Pulling and Skin Picking Disorders

Awareness Week
October 1-7, 2012
From the Hands-Down-a-Thon to Trekking for Trich, distributing brochures to speaking at your school, the time to start planning your Awareness Week Outreach is now! Turn to page 6 for details of the various ways you can make SOME NOISE for BFRBs.

TLC Founding Member Joan Kaylor Launches First App for BFRBs!
“Secrets of Pulling & Picking” is now available in the iTunes and Google app stores.
Joan Kaylor, MSEd, LPC, NCC, founding TLC Board member and recovered trichster, wanted to create a tool that was accessible instantly via smart phones (except while driving of course). She envisioned something to help pullers and pickers alike through urges one moment at a time. Joan invites you to download her app ($2.99), listen to her message and breathe along with her. Thus, here is another strategy for your tool kit.
Join Joan on Facebook at Facebook/Secrets of Hair Pulling and Skin Picking or www.JoanKaylor.com to learn more about Joan, her methods, and her app!

Volunteer Opportunities

Online Support Group Moderators
Under the direction of Christina Pearson, Online Support Group Moderators will assist with the moderation of TLC’s various online support groups. Volunteers should be a current member of at least one of TLC’s online support groups, be fluent in internet-group protocols, and available for approximately five hours a week. Duties include daily approval of new members, monitoring posts each day, reporting questions, issues, or problems to TLC staff when they arise.

Office Volunteer Intern
TLC needs a volunteer to assist with day-to-day operations at TLC Headquarters in Santa Cruz, CA. Volunteer duties will vary from administrative work to event support, plus special projects as assigned. The ideal candidate lives in or near Santa Cruz, CA, and is available approximately 5 hours per week.

For students in the South San Francisco Bay Area or Los Angeles, CA, TLC offers internship and senior project opportunities in the areas of PR & marketing, event planning and nonprofit management.
For more details on these positions, or to apply, visit: http://www.trich.org/involved/volunteer.html or call Leslie at 831-457-1004.
2012 Hands-Down-a-Thon & NEW Trek for Trich and Skin Picking

Both are as easy as 1-2-3!

1. Create a personal fundraising page at TLC's FirstGiving.com homepage.
   
   You can create your own fundraising page in just 10 minutes. (It really is easy and quick to do!) Just go to http://www.firstgiving.com/trichlearningcenter and click the "Get Started" button. Under events, select "Hands-Down-a-Thon" or "Trekking for Trichotillomania & Skin Picking."

   Once your fundraising page is created, you then email a note to friends and family that links to your page, where they can make a donation to TLC in support of your activity. Your sponsors will receive a receipt for their donation, and TLC will receive the funds directly from firstgiving.com.

2. Set your goal.

   For HDAT-ers, set yourself a personal trich or skin picking management goal for the two months of the Hands-Down-A-Thon and monitor your progress. Your goal might be to have a "pull/pick-free day" or to limit your pulling or picking in certain ways (duration, location, etc.). We particularly like goals that involve "using your tools": it might be to use the self-help sites StopPulling.com or StopPicking.com, or to meditate every morning and keep a daily journal as part of building your self-awareness.

   For Trekkers, you may decide to walk for 2 or 20 miles, swim across a body of water, or hike from Maine to New York. Christina would like all treks to take place during National Trichotillomania and Skin Picking Awareness Week, October 1-7, 2012. Whatever goal you set, it should be something that will be challenging, but also something you think you can achieve, so that you will stay motivated and positive.

3. Spread the word and update your sponsors on your progress!

   Through the FirstGiving site, you will email a note to friends and family that links to your fundraising page. You can personalize your page with your story, photos, or a fundraising goal. You can also link your page to your Facebook Account, YouTube Videos, or other websites. TLC's page will track the most successful individual and team fundraising efforts.

   There are more fundraising tips at http://help.firstgiving.com/fundraising-tips

   There's Help Along the Way

For Hands-Down-A-Thon-ers:

- E-Mail Group
  
  When you sign up for this event you will be joined to a TLC-moderated email group, so we can all cheer each other along and share goals, strategies, successes and challenges.

- A Free Month at StopPulling.com or StopPicking.com
  
  TLC has partnered with the online behavior management websites StopPulling.com and StopPicking.com. Hands-Down-A-Thon-ers who use one of these sites for a month will get the second month free. (A promotional code will be emailed to all FirstGiving.com page owners.)

- StopPulling.com and StopPicking.com are websites designed by a member of TLC's Scientific Advisory Board, Suzanne Mouton-Odum, in collaboration with several colleagues. These sites ask you to track your daily pulling and picking behaviors – where they happen, what you are feeling when they happen, and how severe they are – in order to help you attain greater awareness of your patterns. The sites then suggest behavior management strategies that are customized to help you to gain greater understanding and control of your triggers and responses.

Mid-Point Conference Call with Christina Pearson

Halfway through the Hands-Down-A-Thon, on September 27 at 2pm Pacific/5pm Eastern, Christina Pearson will lead a group teleconference for Hands-Down-A-Thon-ers to help keep up motivation, discuss difficulties and brainstorm ways to meet your goals.

Good Luck!

Please note: The Hands-Down-A-Thon is intended for adult participants. If children or teens want to participate, this should be done with thoughtful consideration and parental involvement.

Visit www.trich.org for more ideas on how YOU can MAKE SOME NOISE during National Trichotillomania and Skin Picking Awareness Week.
The three-night Retreat, located on 104 acres of redwood forest in the Santa Cruz mountains, provides an opportunity to step away from regular patterns and surroundings and develop new strategies to increase quality of life while dealing with BFRBs. The three-night Retreat, located on 104 acres of redwood forest in the Santa Cruz mountains, provides an opportunity to step away from regular patterns and surroundings and develop new strategies to increase quality of life while dealing with BFRBs.

Hair pullers and skin pickers of all ages, and their families, are invited to learn and heal, surrounded by a supportive community, at the Annual TLC Retreat.

The Retreat is for those who:

• Seek effective tools and a reduction of picking & pulling behaviors, for yourself or a loved one
• Experience shame, hopelessness, frustration as a result of these behaviors
• Feel as if you have tried everything
• Need a motivational refresher course
• Suffer seeing a loved one struggle with these problems
• Seek a better understanding of how to help your child
• Ages 8 to 88 years old

TLC’s Annual Retreat offers the only experience of this kind in the world.

The Retreat is facilitated by a hand-selected group of expert clinicians and facilitators. Their understanding of these behaviors is rivaled only by the warmth, humor and compassion they bring to each workshop.

2012 Facilitators include:

Merrill Black, LCSW, Relix Master
Christine Fiorentino
Dana Marie Flores
Ruth Golomb, LCPC
Jennifer Landon, LPC
Marti specializes in delicious and healthy organic meals, serving homemade fresh bread and organic coffee.

Accommodations

Choose between all-inclusive, on-site lodging (meals and workshops included), or day participation, which includes meals and workshops only.

Sangha House: a four-bedroom lodge (each room sleeps 4-5, with bunkbeds) with a full kitchen and two group bathroom. For adult women only. NEARLY SOLD OUT!

Cabin: sleeps 4-6 people, may also bring your own tent or camper. Hook-ups are not available.

TLC-provided tents sleep two, air mattresses are provided. You may also bring your own tent or camper. Hook-ups are not available.

TLC Tent 425.00 375.00 525.00
Cabin 575.00 425.00 675.00
Sangha House $695.00

Transportation & Registration

TLC offers charter bus service from San Jose International Airport (SJC) for an additional fee.

Shuttle departs from and returns to SJC. The shuttle will depart from SJC airport at 4pm SHARP on 9/20/12, and depart from Pema Osel Ling at 11:50AM on 9/23/12.

Your flight must ARRIVE BEFORE 3:00pm on 9/20/12, and DEPART AFTER 2:00pm on 9/23/12 to take advantage of this service. Sign up for the TLC Shuttle upon registration.

Shuttle departs from and returns to SJC. The shuttle will depart from SJC airport at 4pm SHARP on 9/20/12, and depart from Pema Osel Ling at 11:50AM on 9/23/12.

What’s included with registration?

Day participant rates include all of the above with the exception of lodging. A list of hotels in the vicinity is available upon request, or on our website. Please note the nearest hotel is 30 minutes down a windy mountain road.

Day participant 375.00 325.00 475.00
Your Own Tent 395.00 355.00 495.00
TLC Tent 425.00 375.00 525.00

Sangha House, Cabin and Tent rates include three nights lodging, dinner Thursday evening, breakfast, lunch and dinner Friday and Saturday, and break fast on Sunday. All workshops and group activities are also included. Attendees must bring their own toiletries and bedding.

Attendees may wish to bring additional funds to pay for extra services like massage, facials, or gifts/sundries from the retreat center gift shop.

Flexible payment plans are available!

Contact leslie@trich.org or call 831-457-1004 to learn more about fee-assistance programs.

Questions? 831-457-1004

Comprehensive education on BFRBs is presented, while introspection, contemplation, meditation, and experientially focused workshops are part of the Retreat process.

Topics include:

• Cognitive Behavioral change strategies
• Motivation & readiness for change
• Mindfulness & self-awareness training

There is also time to swim, hike, relax, get a facial, haircut, or massage (extra fees apply for these services).

Learn from caring experts

The positive impact of [the TLC Retreat] has spread across many aspects of my life - like having more self acceptance and compassion for myself and others.”

Dana Marie Flores
TLC Board Member

Register by phone 831-457-1004 or Online: www.trich.org

What a transformation. Thank you for accepting the vulnerability that we must be in to transform.

—Brenda

The positive impact of [the TLC Retreat] has spread across many aspects of my life - like having more self acceptance and compassion for myself and others.”

Dana Marie Flores
TLC Board Member

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Dana Marie Flores
TLC Board Member

“[The Retreat] is one of the more amazing experiences of my life...”

-Charles Mansueto, PhD, 21-year Retreat Presenter

21st Annual TLC Retreat
Updates from TLC Research Partners
Continued from page 1

Updates from Jon E. Grant, MD, JD, MPH
Dep't. Psychiatry and Behavioral Neuroscience
University of Chicago

Dr. Grant and his research team are wrapping up several exciting projects. While he cannot provide much detail on the studies themselves, (as he cannot divulge findings before they are published), he was kind enough to allow us to share the following teasers about his most recent work:

The first brain imaging study in skin picking disorder is now finished. This will be the first evidence showing what we have all known: that there are differences in the brains of people who pick compared to people who do not. I think this type of research will further support the idea that this is not a character problem but instead an actual brain illness.

We are about one month away from finishing our large treatment study of naltrexone for trichotillomania. Results will be known later this fall.

We have a review article on Skin Picking Disorder (written with Brian Odlaug, Sam Chamberlain, Dan Stein and Nancy Keuthen) that will be coming out in the next couple months in the American Journal of Psychiatry. This is the first article this journal has ever published on skin picking and it should inform clinicians around the world about this problem.

Steped Care in Treating Trichotillomania
David A. F. Haaga, PhD
American University

Since 1997 I have directed a psychotherapy training clinic (now known as the James J. Gray Psychotherapy Training Clinic in honor of the founding director of clinical training in our clinical psychology PhD program) at American University, staffed by doctoral students. Over the years, I noticed repeatedly that our clients with trichotillomania (TTM) entered treatment having suffered for a long time and having had considerable difficulty finding therapists with TTM expertise. Large-scale survey research conducted by members of the TLC Scientific Advisory Board confirmed that my anecdotal observations were typical. For instance, only 3% of respondents to an internet survey had received treatment from a professional they considered to be a TTM expert (Woods et al., 2006).

I therefore took an interest in the issue of access to high-quality care for TTM. In May 2010, with support from the National Institute of Mental Health, my students and I, along with our biostatistician collaborator Dr. Betty Malloy, have been studying stepped care for TTM. “Stepped care” refers to using low-cost, less intrusive treatments first and reserving higher cost and/or more intrusive interventions for those who do not respond well enough to the initial treatments. For example, if someone has borderline hyper-tension, a low-salt diet and moderate exercise program might be tried first, followed by progressive muscle relaxation training. Antihypertensive medication regimens would be used only if the first treatment steps did not work well enough.

In principle, stepped care schemes improve overall access to effective treatment, relative to more haphazard means of allocating treatment resources, because the most expensive or specialized treatments are reserved for those who really need them because they are unable to benefit from more widely available or simpler interventions. To put it in a local TTM context for the Washington DC area, each client who can get better by working with a self-help web-based help phase, participants have the option of continuing to step 2, an 8-session course of habit reversal training conducted at our training clinic by graduate students under my supervision. TTM symptoms, overall quality of life, and satisfac-
tion with treatment are assessed after step 1, after step 2, and again 3 months later.

This research is ongoing, but our students have begun to examine several issues related to measurement or treatment of TTM. A few examples are summarized below:

1. Rusch et al. (2012) found that participants who did not meet DSM-V diagnostic criteria for TTM had more severe symptoms than those who did. This suggests that there may be a range of severity, distress, and functional impairment. Paper presented at the 19th annual conference of the Trichotillomania Learning Center. Chicago, IL.

2. Banis et al. (2012) studied correlates of motivation to seek treatment for TTM. Our participants endorsed intrinsic motivations to change (e.g., “I would like to make changes to my behavior because it is important to me”) and extrinsic motivations (e.g., “Because other people think it’s a good idea for me to be in therapy.”) Total (intrinsic + extrinsic) motivation was positively correlated with the amount of time participants reported spending on an average day pulling their hair or thinking about pulling. Otherwise, motivation scores were uncor-related with TTM severity, distressed associated with hair pulling, or the percentage of participants reported experiencing as a function of hair pulling.

3. McDonough et al. (2012) found that self-reported and inter-viewer-rated TTM symptom severity measures were positively correlated with one another, which supports the validity of these measures. Neither measure of TTM symptom severity was significantly correlated with severity of anxiety or depressive symptoms.

4. Falkenstein et al. (2012) studied the role of intrinsic motiva-
tion in predicting who would maintain symptom improve-
ments made after HRT. Data collection for this study is ongoing, but we hypothesized that higher intrinsic motivation was positively correlated to treatment that did not predict how well participants were able to sustain improvements made during HRT to the time of our 3-month follow-up evaluation.

We expect to complete data collection in Fall 2012 and look forward to analyzing results with respect to our main overall re-search questions. These include the impact of web-based self-help as a treatment step (to our knowledge, this will be the first controlled study of the effects of use of StopPulling.com) and the validity of several alternative decision rules for identifying a treatment step as having had sufficient impact.

Acknowledgements
We appreciate the help of the Trichotillomania Learning Cen-
ter, Inc. (Christina Pearson, Founding Director), StopPulling.com (Drs. Suzanne Mouton-Odum, Melinda Stanley, and Nancy Keu-
then, Developers), and numerous colleagues who treat and/or study TTM in publicizing our research to prospective participants.

Progress in this research is primarily attributable to the hard work of a number of students: Kate Rogers (Project Director), Maria Banis, Emily Edwards, Martha Falkenstein, Lauren Mc-
Donough, Sam Nelson, and Natalie Rusch (Research Assistants); Martha Falkenstein, Erica Hart, Jessie Hutchison, Kate Rogers, Natalie Rusch, & Lauren Skalina (HRT therapists).

References

Role of Microglia and Trichotillomania Onset
Mario R. Capecchi
Distinguished Professor, Human Genetics and Biology Investigator, Hoggard Huck M.D. Institute
University of Utah School of Medicine

Last year, many TLC members donated bone marrow to help further Dr. Capecchi’s research into possible molecular causes of trichotillomania. TLC recently asked Dr. Capecchi for an up-
date on his work, and he has reported, “We have had to do many more pilot experiments to optimize the bone marrow transplant procedures. These experiments take many months to complete before the results are apparent. Once the condi-
tions of the experiments are well defined, we will then start them. Unfortunately, the results are not likely to be available for at least a year. Again, thank you and members of TLC for all of your participation in our research and we look forward to the results.”
with trichotillomania, twelve unaffected first-degree relatives of those subjects with trichotillomania, and twelve matched healthy controls with no known family history of trichotillomania or body-focused repetitive behaviors.

Mr. Odaugas is a PhD candidate who has a long history of conducting clinical trials in impulse control disorders through his mentorship with Dr. Jon Grant, Professor of Psychiatry at the University of Chicago. His academic work in public health led him to understand the need for intervention for undiagnosed and misdiagnosed conditions such as trichotillomania and pathological skin picking. Brian has authored or co-authored over 30 articles and book chapters on the epidemiology and treatment of body-focused repetitive behaviors and presented research at domestic and international venues.

Dr. Chamberlain, Senior Visiting Clinical Research Fellow at Cambridge University, is a well-respected researcher and clinician with special interests in translational approaches to trichotillomania and related impulse disorders. He has considerable experience in the design, running, and interpretation of clinical trials and proof-of-concept studies in various contexts, including in people with trichotillomania and other BFRBs. His focus is on the application of neuroimaging and cognitive testing to dissect the neurobiology of these conditions and effects of novel centrally acting compounds. 

Intervention in Learning More?

This study will be conducted at the University of Chicago and will involve one 3-hour visit where the individual with TTM and the first-degree family member would come in together. Compensation will be provided, although travel to the study center from outside of the Chicago area will not be covered. If you are interested in learning more, please contact Brian directly at odaugas@uchicago.edu.

2. Neural Correlates of Symptom Change in Behavior

Therapy for Pediatric Trichotillomania

Tara S. Peris, PhD
Assistant Professor, Dept. of Psychiatry & Biobehavioral Sciences
Semel Institute for Neuroscience & Human Behavior
University of California, Los Angeles

This study examines the effects of behavior therapy (BT) on the brains of children with TTM. Behavior therapy is a specific type of treatment that teaches children to become more aware of their hair pulling and unrelated behaviors and to develop alternative strategies for responding. Studies show that BT can be very effective for youth with trichotillomania; however, many questions remain. Most importantly, although we know that BT works to reduce symptoms of TTM, we still don’t know how or why it helps youngsters to get better.

Dr. Peris is a Assistant Professor in the Department of Psychiatry and Biobehavioral Sciences at the UCLA School of Medicine and an Attending in the UCLA Child OCD, Anxiety, Tic, and Related Disorders Program. She will have overall responsibility for the study design, outcome assessment, and data analysis. Dr. Peris is an expert in the assessment and treatment of childhood OCD and related disorders and she has considerable experience with pediatric TTM. In addition to direct treatment experience, she has led focus groups for adolescents with TTM and their parents and she has supervised numerous TTM cases. She is the recipient of a career development award from NIMH, a NARSAD Young Investigator award, and a grant from the Obsessive Compulsive Foundation.

Progress Report:

Testing for Biomarkers & Mechanisms of NAC Efficacy in a Mouse Model of Trichotillomania

Amy Lossie, PhD
Assistant Professor, Dept of Animal Science, Purdue University

Dr. Lossie’s study, in partnership with Dr. Joseph Garner, TSLC Scientific Advisory Board member, and Giovana Vieira, a PhD student at the University of California, Los Angeles, was funded to identify whether N-Acetylcysteine (NAC) is efficacious at reducing symptoms of Trichotillomania in adults.

Dr. Lossie’s project focuses on two goals: 1) Identifying how NAC works in the brain to treat symptoms of TTM, and 2) Developing a potential blood- and urine-based test, called biomarkers, that could lead to screens that predict risk for developing TTM, as well as help in the identification, diagnosis, and personalized treatment of individuals with TTM.

“It has been quite an exciting year for us, as our TSLC-sponsored research projects have demonstrated promising new insights into the mechanisms of Trich,” reports Lossie. The research team has made some preliminary breakthroughs that strongly suggest that oxidative stress plays a major role in the development of barbering (a model of trich) in mice.

At the TSLC Conference in Chicago this past May, Giovana presented her findings that dysregulation of several key markers of oxidative stress occurs in mice that barber. Most exciting, she demonstrated that treating mice that are predisposed to barbering with a widely available antioxidant, N-acetylcysteine, prevents and cures barbering in over 50% of animals. The team conducted a large-scale gene expression study in these studies, in the brain, and look forward to sharing these results with the membership at the 2013 TSLC Conference in New Jersey.

Progress report:

N-Acetylcysteine for the Treatment of Pediatric TTM

Michael H. Bloch MD, MS, and Karin L. E. Panza, BA
Yale Child Study Center

Preliminary results of this study were presented at the 2012 TSLC Conference. Thirty-nine children with trichotillomania were randomized to NAC or placebo. We found that NAC was significantly more effective than placebo in reducing symptoms of pediatric trichotillomania. However, we found that children in both the placebo and NAC groups significantly improved during the course of the 12-week trial. Additionally, side-effects from NAC treatment were similar to that observed in placebo. However, one child had an allergic reaction to the active NAC tablets.

The results are different than a previous placebo-controlled trial in adults with trichotillomania, which casts a large and statistically significant benefit of NAC. Possible causes for these differences may attributed to the following theories: (1) hair pulling may be a fundamentally different disorder in children and adults; (2) differences in trial design of the two studies may have led to differences in results; and/or there may be a specific subset of patients with TTM who respond to NAC. Children with trichotillomania report less awareness of urges and less focused pulling than adults with TTM. NAC works by reducing the urges associated with TTM, one would expect it to be less effective in children.

Subjects in the pediatric NAC trial were seen more frequently, emphasizing the importance of the trial, compared to the adult trial. More frequent monitoring, support and psychoeducation regarding trichotillomania may have caused more improvement in trichotillomania regardless of the pharmacotherapy subjects were on. It is also possible that the true effect of NAC may be somewhere in-between the reported effect observed in adults and children. More research needs to be done to verify its efficacy.

This trial highlights the need to focus on understanding the developmental and clinical course of this condition in children. Specifically, longitudinal studies examining the likelihood of recovery over time are critical to properly understand, treating and researching this condition. It also emphasizes the importance of referring children with TTM to specialty behavioral therapy, which has been shown to be effective in children, before initiating any pharmacological interventions.

Progress Report:

Computerized Cognitive Training Programs for TTM

Han Joo Lee, PhD
Assistant Professor, Dept of Psychology
University of Wisconsin-Milwaukee

This study aims to examine the feasibility of a computerized treatment that specifically targets poor response inhibition, which is suspected to be an important cognitive deficit underlying TTM. To this end, young individuals aged between 12 and 17 with TTM have been randomly assigned to the response inhibition training condition (RIT) vs. a waitlist control condition (WLT). Participants in the RIT condition receive eight 30-min training sessions over a 4-week period and are assessed at three time points (baseline, post-treatment, and 1-month follow-up). Participants in the control condition are assessed at baseline and after a 1-month wait period, and they are also invited to receive the RIT after completing the study procedure for replication purposes.

Upon establishing efficacy, the computerized treatment may be easily integrated into various contexts. For example, as an adjunctive intervention to existing behavioral and/or pharmacological treatments, an instrument to identify and help-at-risk individuals, or as a prevention strategy to reduce the risk of intervention, and/or a remote web-based self-help intervention.

Currently, a total of 13 participants have completed the study and there are four potential participants who are being evaluated for participation. Participants have responded to the RIT intervention without reports of any adverse events. Please contact the Han Joo Lee, PhD, with inquiries or referrals of potential participants: (414) 229-5855 or TrichStudy@gmail.com.

Progress Report:

Trichotillomania International Consortium for Research

Lead Investigator: David Pauls, PhD
Director, Psychiatric & Neuromodulatory Developments Unit
Massachusetts General Hospital

The Trichotillomania International Consortium for Research remains TLC’s most ambitious project to date. This project’s primary goals are 1) to facilitate research into the genetic underpinnings of trichotillomania and skin picking disorder, and 2) to leverage the findings of the Trichotillomania Impact Project (a web-based survey) with face-to-face clinician interviews in order to more strongly document the “disease burden” and thus strengthen the case for large-scale funding of research.

To these ends, TLC has sponsored the development of a consortium of multidisciplinary TTM researchers, led by members of the TLC Scientific Advisory Board, to collaborate on genetics research and other future endeavors. We have established a biobank of DNA samples and a database for phenotype data at Massachusetts General Hospital/Harvard Medical School, as well as the University of Cape town and the University of Stellenbosch in South Africa. TLC plans to establish additional sites in the near future.

By recruiting investigators from multiple sites, adequate sample sizes can be achieved more rapidly and clinical information can be aggregated for pooled analyses. The centralization of genetic and clinical data will also have the benefit of allowing future researchers to empirically test hypotheses with information from these databases, thus eliminating the need for recruitment of additional samples.

As reported last year, the pilot study for this project was successful. Good progress has been made; researchers at Massachusetts General Hospital/Harvard Medical School. In addition, data collected for the TTM Family Study have also been deposited in the biobank. The findings of the pilot study hold promise for assessing approximately 160 samples of subjects with trichotillomania, and cell lines have been created for each.
What’s on MY mind is Life Transformation.

I recently took a trip to London to visit Lucinda Ellery and her salon – she will be opening another in Los Angeles this fall. Lucinda has long been one of the few trich-resources in England, but before this year we had spoken just once 20 years ago – the problem of distances and money keeping us apart. Turns out Lucinda is my heart’s galactic Star Sister; we can almost complete each other’s sentences. And we are both passionate, beyond words, about our work with trich. Were we separated at birth? Before this year we had spoken just once 20 years ago – the problem of distances and money keeping us apart. Turns out Lucinda is my heart’s galactic Star Sister; we can almost complete each other’s sentences. And we are both passionate, beyond words, about our work with trich.

Today I can say this: I am profoundly grateful to ALL THAT IS (my "definition" of ultimately utterly undefinable God/Universe/ Love-Beyond-Comprehension) for the amazing ability to actually change our mind, our worldviews, our belief systems. To take the risk of developing willingness to be open to new perspectives, that once were too "foreign" to even consider embracing.

It has been SO fun - to simply play a bit with makeup, hair, clothes! It has not increased my sense of core value, I already profoundly understand that I am precious, beloved – as are you. But it has expanded a sense of freedom, freedom to play in areas where I was too fearful most of my life. And it is SO funny, to observe the difference in how people interact with me, both men and women. And a big thank-you to darling Lucinda, who invited my woman-child to come out and play! Lucinda and I will be doing a lot of projects together from now on. You’ll see it has been a great internal healing for me, and I am delightedly, unabashedly - grateful!

I am beginning, for real, to be comfortable, in my skin and in my Life.

Much love, Christina

"I've been a treasured, shining, coveted, vulnerable, desperate, caring, fumbling, desperate, vulnerable woman-child within my heart, the core of my early life experience, is blending finally into ME. She yearned to feel okay, be comfortable in her skin. I am beginning, for real, to be comfortable, in my skin and in my Life."

Jennifer Raikes
Los Angeles, CA
jen@trich.org

Executive Director’s Report

Nancy is a power-house – brilliant, hard working (to put it mildly) and deeply caring. She is an associate professor of psychology at Harvard Medical School and has been a key part of TLC and the SAB for nearly two decades. Her accomplishments are too many to list, but a few of the most significant to our community: she co-directs the Trichotillomania Clinic at Massachusetts General Hospital, authored the popular book "Help For Hairpullers," and is the co-PI of the "Family Study" – the largest privately funded research study examining the genetic and emotional/family dynamics involved in the expression of trichotillomania.

I am deeply grateful to Nancy for giving herself to our cause so wholeheartedly and for the great expertise she has provided to our development. The SAB Chair also serves as a Member of TLC’s Board of Directors, giving that individual a unique perspective on all aspects of TLC’s mission. I asked her to reflect for us on her experience with TLC over the last six years as SAB Chair, which has been a time of great progress and growth.

Nancy Keuthen: When I reflect back on my tenure as chair of the SAB, what I am most struck with is the incredible synergies that exist between the SAB, TLC and our wonderful constituency. The SAB is comprised of accomplished researchers and expert clinicians from many of the best academic and medical institutions. Yet without TLC and those who deal with trichotillomania and skin picking every day, we would not be able to make our contributions. TLC initially brought us all together, provided us with the necessary infrastructure, and has funded many of our clinical and research initiatives. The TLC community has willingly participated in our research endeavors and so generously shared with us their private stories so that we can, in turn, help others.

Julie and I have collaborated and complemented each other every step of the way. We all share in the credit for how far the field has come. There have been so many wonderful projects and initiatives accomplished by the SAB over this time. I fear that I may omit an important one that is near and dear to someone...so please know that I have truly valued every effort and achievement.

As a researcher, what first comes to my mind are several of the collaborative research efforts, including the Trichotillomania Impact Projects (TIP), the TRIC Research consortium that developed the DNA biobank for trichotillomania, and the research efforts that contributed to changes in the upcoming DSM-V manual.

On the clinical front, our talented clinicians have trained so many professionals through conferences, workshops, PTIs, webinars and training videos. It is so gratifying to think about the multiplicative effect as these professionals will then educate and train other colleagues and students. Last, but not least, I am grateful for the many educational materials that SAB members and TLC staff developed, for professionals of many different disciplines, to elevate awareness and provide basic education on the disorders.

We have all truly been pioneers these past few years, and have many accomplishments of which to be proud. That being said, we still have much work to do in unraveling the neurobiological underpinnings of these disorders, advancing early detection and treatment, developing more effective and enduring treatments, further elevating public and professional awareness, and better disseminating our treatments to other professionals.

It has been a wonderful odyssey for me as chair of the SAB. I would like to thank each and every one of you for your personal and professional support over the years. And it is with much excitement that I look forward to my new role as vice-chair! Thank you, Nancy, for your remarkable work to end the suffering caused by hair pulling and skin picking.

Much love, Jennifer

Jennifer Raikes
Los Angeles, CA
jen@trich.org

Executive Director’s Report

Dear Friends,

For this special “research” issue of In Touch, I am taking my ‘space’ to say a heartfelt thank you to Nancy Keuthen, PhD, who recently completed her tenure as Chair of TLC’s Scientific Advisory Board. (Don’t worry, we haven’t let Nancy go far – she’s going to continue to serve on the SAB as Vice-Chair.) The wonderful Jon E. Grant, JD, MD, MPH, has been elected as the new SAB Chair – Welcome, Jon!

TLC’s Executive Board welcomed Nancy to its ranks in 1998, and her leadership has been critical to the organization’s growth and success. Her energy and dedication have been infectious to our entire community.

Nancy says she was "blown away" by my appearance... because it made me feel good. I did what I needed to do to feel better and express my true self. It was only after this happened that I realized I was-growing and therefore-the risk of developing willingness to be open to new perspectives, that once were too ‘foreign’ to even consider embracing.

Thank you, Nancy, for your remarkable work to end the suffering caused by hair pulling and skin picking.

Much love, Jennifer

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Executive Director’s Report

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On a Memorial Day weekend twelve years ago, our daughter (almost nine years old at the time) pulled half of her eyelashes. The effect upon her and the whole family was profoundly unsettling and disruptive.

In her suffering, she was unable to explain what she had done or why she had done it. As parents, we loudly demanded that she change her behavior. Even though she was not quite nine years old, we thought that she could control this behavior when presented with a high enough level of threatened punishment. How sadly mistaken we were.

We went from psychologist to psychologist. None knew how to treat Trich. One psychiatrist put our beautiful daughter on a medicinal regimen that actually aggravated the urge to pull. It was the worst month of pulling in our daughter’s life.

For those who have a loved one with this disease, we don’t have to tell of the heartbreaking emotions, rejections and whispered slights felt by the sufferer. The isolation is compounded when in public. The looks of shock and surprise are hard not to notice.

We do not recall how we came to know of TLC, but we will never forget the first time calling and hearing Christina’s calm and reassuring voice on the other end. She reached out and touched these bewildered parents.

It is vital to learn the causes and contributing factors of trichotillomania. Only then is it possible to test and compare different treatment modalities. This can only be accomplished through research – and good research costs money.

We are grateful for the unceasing generosity and efforts put forth by Christina and her cohorts and supporters at TLC. We would not know of this disorder were it not for the suffering of our daughter. We consider it a privilege to be able to help bring comfort and knowledge to other sufferers and their loved ones. We are humbled by the true compassion that Christina and TLC bring to helping others to learn to cope.

As recipients of this largesse, we believe it an honor to contribute on an annual basis to help continue this mission.

Working together, we will find more effective treatment, and an eventual cure.

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Thank you for being part of the solution.

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831-457-1004 • www.trich.org • info@trich.org

Working together, we will find more effective treatment, and an eventual cure.

Make Your Voice Heard: Give Today