The Role of the Family Environment in Adolescent Hair Pulling

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Editor’s Note: Here at TLC, we have anxiously awaited publication of the results of this study, which is also the largest privately-funded trichotillomania study to date. This article is a synopsis of a peer-reviewed article published in the “Journal of Obsessive-Compulsive and Related Disorders,” Volume 2, Issue 4, October 2013.

There have been longstanding questions regarding the relative contributions of nature (genetics) vs. nurture (environment) to the development and maintenance of many psychological problems. Until recently, there has been little investigation of this issue in the field of TTM.

Several years ago we had the good fortune to receive funding and much inspiration to explore the TTM family environment as well as the familial transmission of TTM and co-occurring obsessive compulsive behaviors and other psychiatric disorders. This Family Study was privately funded by The Timothy Fund (a fund within the Greater Kansas City Community Foundation). This Fund supports the objectives of a 20-year member of TLC who has been inspired by the work of Christina Pearson (Founding Director of TLC who now runs the Heart and Soul Academy). The Timothy Fund also financed two genetic

Commentary on The Role of the Family Environment in Adolescent Hair Pulling

Christina Pearson, TLC Founder
www.christinapearson.com, christina@christinapearson.com

As the woman who created TLC, writing a commentary on this groundbreaking, incredibly important research study is deeply meaningful as it validates much that I have experienced and seen. Let me explain:

I call this project groundbreaking, because it looks right into the fishbowl of OUR family life. That, my dear friends, is a risky endeavor, because no one wants to be found finding fault with the family!

What it finds is basically this: in households with an adolescent with trich there tends to be more tension and stress. What it DOESN’T do is determine if the trich is the source of the stress, or was the stress, etc., there BEFORE the trich. What it DOES do, is bring our attention to a problem in the family ‘emotional resonance’ and the differing perceptions of the discordance level of that resonance - from both the adolescent and parent perspective.

I feel this study helps tremendously in pushing us to consider the much bigger picture; instead of just searching for a pill to eliminate the behavior, we need a much clearer, richer understanding of the interactive process of biology and environment... with interpersonal family dynamics being a recognized player.

So do I think that a dysfunctional family is the single root cause of TTM? No, I do not. If it were, not only would my siblings all pull (and they don't), my hunch is there would be more people suffering with pulling and picking, to the tune of tens of millions. But I do think that forms of family dysfunction play a tremendous role in creating conditions in which a hyper-sensitive, highly empathic child with certain genetic propensities can become what I call “systemically overwhelmed” by

Skin Picking: From a Male Perspective...
SkinPick Guy
diaryofaskinpicker.tumblr.com
New York, NY

I am male and have suffered from Skin Picking Disorder for 20 to 30 years. I've had it for most of my life and I can't even remember when I first started picking. It's just a part of my life. Sometimes my picking can be out of control where I pick for hours a day, while other times I don't even think about it and don't pick at all.

I think there are a few differences between my experience and that of a woman with the same disorder. Perhaps the biggest stone is make-up. I don't wear make-up, thus I can't easily hide my scars or scabs. On my blog, I read a lot of posts where people have tips for covering up with make-up, or asking which make-up products are good for covering scars. I don't really get to do that. My face is always my own bare face with all the scars, scabs, spots and other imperfections.

I remember many times when I picked my face in the morning and then had to go to school or work. I had to quickly try to stop the bleeding and then somehow avoid bleeding throughout the day without wearing make-up or putting on a band-aid. Usually I would leave the house with a few napkins so I could quickly mop up any blood oozing out of my wounds on my way to work and hope that it would stop bleeding by the time I got there. I don't usually pick my face, at least not

Inside this issue:
- Upcoming Events
- Professional Training Grads!
- Executive Director Report
and more...
Webinar: Managing your BFRB when Life Happens
December 11, 2013 with Fred Penzel, PhD
11:00am PST / 12:00pm MST / 1:00pm CST / 2:00pm EST
You have found a treatment that works, you have a strong support network, and you are on the road to recovery…then life happens. Stressors big and small come into play when working on your recovery. Join Dr. Penzel as he discusses solutions for dealing with life changes while managing picking and pulling behavior.

Austin, Texas: One-Day Workshop
February 1, 2014 with Suzanne Mouton-Odum, PhD
Hosted by the Austin Trich Support Group
Adults, parents, teens and clinicians are invited to attend an educational workshop on hair pulling and skin picking disorders. TLC-Scientific Advisory Board Member, Suzanne Mouton-Odum, PhD, will be joined by former board member, physician and parent, Jackie Abrams, MD. Details are still coming together as of press time, please check www.trich.org for more details.

Toronto, Ontario, Canada: One-Day Workshop
April 5, 2014 with Jon Grant, MD, JD, MPh, Peggy Richter, MD, FRCP, and Mark Sinyor, MSc., MD, FRCP
Save the date! A one-day educational event for anyone affected by BFRBs, our esteemed panel will discuss effective treatment approaches, including medication, cognitive behavior therapy, and mindfulness. The newly formed Canadian BFRB Support Network will also be on hand to share the exciting local resources they have developed across Canada. Please check our website in January for registration and location information.

TLC Annual Conference: Registration is open!
April 25-27, 2014
Renaissance LAX Hotel, Los Angeles, CA
The TLC Conference is the only event of its kind: over 500 people of all ages, parents, and treatment providers come together. Build your own program of education and recovery from a comprehensive schedule of over 60 expert-led seminars, covering topics from treatment and research to self-help and parenting.

Learn more about the Conference and other TLC events on our website: www.trich.org or by calling 831-457-1004.

Researcher Wins Award for TLC-Funded Study
The American Academy of Child and Adolescent Psychiatry (AACAP) recently announced Michael H. Bloch MD, MS, as the recipient of AACAP’s 2013 Norbert and Charlotte Rieger Award for Scientific Achievement. The award recognizes the best paper written by a child and adolescent psychiatrist published in AACAP’s journal between July 2012 - June 2013.

Dr. Bloch’s study investigated the efficacy of N-Acetylcyisteine for the treatment of TTM in children. TLC funded this study through the donor-supported Research Grant Program in 2009. Participants were recruited via this newsletter, email and website listings. Preliminary results of this study were presented at the 2012 TLC Conference. While investigators found that NAC was not more effective than placebo in treating the symptoms of pediatric trichotillomania, the trial ultimately highlighted the need to focus on understanding the developmental and clinical course of this condition in children. It also emphasized the importance of referring children with TTM to appropriate behavioral therapy before initiating any pharmacological interventions and the need for more research in the BFRB field, particularly within the psychiatric community.

Congratulations to Dr. Bloch and the study’s clinical research coordinator, Karilyn Panzal

New Support Groups
Orange County
Orange County BFRB Anonymous

Philadelphia
Support Group for Skin Picking & Hair Pulling
Support group for people with skin pickers and/or hair pullers of all ages. Fee of $2/pcp to pay for meetup costs/snacks & copies. Participants are urged to make a commitment to attend at least three sessions consecutively. For more info, go to: http://www.meetup.com/Get-Support-for-Hair-Pulling-Skin-Picking-Disorder.

Call for Submissions
Send in Your Stories, Artwork, Poetry
Do you have a BFRB story to tell? TLC is continuously looking for inspiring member stories, case studies, poetry, artwork or other original submissions to share on our blog and in this newsletter.

Written submission should be between 500-2000 words, images should be at least 300dpi and submitted as jpeg or png. Please email your submissions to leslie@trich.org.

TLC Event Calendar

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 diagnosed quickly.
• 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.

TLC Board of Directors
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TLC is a 501(c)(3) tax-exempt organization and all contributions are tax-deductible.

Our Tax ID number is: 77-0266587.

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To submit articles or send letters write to: Trichotillomania Learning Center 207 McPherson Street, Suite H Santa Cruz, California 95060 (831) 457-1004 www.trich.org info@trich.org Editor: Leslie Lee

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Text deadline next issue: January 15, 2014

The information in this newsletter is not intended to provide treatment for Hair Pulling or Skin Picking Disorders. Appropriate treatment and advice should be obtained directly from a qualified and experienced doctor and/or mental health professional. The opinions expressed are those of the individual authors.

News and Announcements

Internet Research Participation Opportunities

Body Dysmorphic Disorder (BDD) and Obsessive Compulsive Disorder (OCD)
Volunteers wanted to help learn about Body Dysmorphic Disorder (BDD) and Obsessive Compulsive Disorder (OCD) in a study being conducted through George Mason University. If you have, or think you have, BDD or OCD, you can contribute to scientific knowledge about risk factors for poor outcomes in these disorders. Participation is confidential and involves completing questionnaires about your experiences online, at your convenience. All participants are entered in a raffle for compensation (up to 75 participants will receive compensation).

If you are interested in participating, visit www.trich.org/enrolled/ research-study.html then click “Internet Surveys” for the survey link.

Development of a Measure of Beliefs in Trichotillomania
Researchers at Swinburne University of Technology (Melbourne, Australia) are currently developing and evaluating a measure of thoughts and beliefs associated with Trichotillomania.

Seeking individuals with and without trich, age 18 and over. Participants will be asked to anonymously complete questionnaires online, which will take approximately 45-60 minutes to complete.

For more information and to be directed to the survey, go to this link: http://www.psychsurveys.org/trichotillomania/beliefs

Regional Research Participation Opportunities

Kent, OH
Children with Hair Pulling Disorder (Trichotillomania) 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 Anxiety Research (CARe) Program is looking for youths who pull out their hair ages 9-17 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 diagnoses and treatment options and referrals. Children can EARN UP TO $75 IN GIFT CARDS for participation.

If you and your child might be interested in this research study, you can contact us at 330-672-2200 or visit our website: www.ChildAnxietyResearchProgram.com

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If you and your child might be interested in this research study, you can contact us at 330-672-2200 or visit our website: www.ChildAnxietyResearchProgram.com
2013 PTI Graduates

Professional Training Institute Class of 2013

The 2013 Professional Training Institute (PTI), held in November in Arlington, VA, was the largest TLC training to date. TLC-SAB members Charles Mansueto, PhD; Fred Penzel, PhD; and Ruth Golomb, MEd, LCPC, facilitated the 18-hour program from which 36 clinicians graduated.

This year, we have also expanded the PTI Faculty. As part of TLC’s goal to expand access to treatment professionals, staff, and the original PTI Faculty identified several clinicians who had previously completed the training program and have, among other criteria, placed themselves as recognized experts in the field. This faculty expansion will allow TLC to offer PTI graduates post-training supervision, a crucial support mechanism to assist trainees in implementing the treatment protocols outlined in the PTI.

Congratulations to the Class of 2013, and much gratitude to Drs. Mansueto and Penzel and Ms. Golomb for their vision and dedication to making access to treatment a reality for all BFRB sufferers.

PTI Faculty:

Charles Mansueto, PhD
PTI Director
Director, Behavior Therapy Center of Greater Washington
Silver Spring, MD

Fred Penzel, PhD
Senior Faculty Director,
Western Suffolk Psychological Services
Huntington, NY

Ruth Golomb, MEd, LCPC,
Supervisory Director
Behavior Therapy Center of Greater Washington
Silver Spring, MD

Renae Reinardy, PsyD, LP
LakeAndee Center for Behavioral Change
Fargo, ND

Stacy Shaw Welch, PhD
Director, Anxiety & Stress Reduction Center of Seattle
Seattle, WA

Suzanne Mouton-oudum, PhD
Private Practice
Houston, TX

Marla Deibler, PsyD
Executive Director
Center for Emotional Health of Greater Philadelphia
Cherry Hill, NJ

Sherrie Vavrichek, LCSW-C
Behavior Therapy Center of Greater Washington
Silver Spring, MD

Jennifer Kessler, PhD
Behavior Therapy Center of Greater Washington
Silver Spring, MD

2013 Graduates

Canada: Toronto, Ontario
Dr. Peggy Richter, MD, FRCP
Anxiety Disorders Centre at the Sunnybrook Health Sciences Centre

California: Walnut Creek
Wendy L. Ritchey, PhD
Ritchey Consulting, Inc.

Colorado: Denver
Jill Kaufman, PhD
Private Practice

Connecticut: Fairfield
Amy Cawman, LCSW
Private Practice

Connecticut: Newton/Sandy Hook
Patricia Becker, LCSW, MSW
Newtown Youth & Family Services

District of Columbia
Irina Amos, PhD
Psychological Assessment Solutions

Georgia: Atlanta
Elana Zimand, PhD
Private Practice

Georgia: Johns Creek
Natalie Amette, PhD
Private Practice

Indiana: Merrillville
Carol Briggs, LCSW, MSW
Regional Mental Health Center

Massachusetts: Northbridge
Ashley Hart, PhD
UMASS Medical School

Maryland: Bethesda
Jennifer Fajjar, LCPC
Gunzenberg & Associates

Maryland: Silver Spring
Caitlin Condit, BA
Behavior Therapy Center of Greater Washington

New Hampshire: Keene
Kathleen Rymes
The Brattleboro Retreat

Ohio: Mason
Jennifer Wells, MSW, LSW
Lindner Center of Hope

Ohio: Worthington
Azaria Ashki, PhD
Private Practice

Pennsylvania: West Chester
Susan E. R. Mitchell, PsyD, LLC
Private Practice

South Carolina: Myrtle Beach
Tammy Houtches, MA, LPC, NCC
Inlet Counseling Center

TLC Conference . April 25-27, 2014 . Los Angeles, CA

Recognize the need to support awareness and outreach for trichotillomania and skin picking?

Want to expose your brand to over 30,000 web visitors per month?

Compelled to participate in an event that many refer to as life-changing?

The TLC Annual Conference offers a unique opportunity to reach a specific demographic while supporting the only event of its kind in the world. With a comprehensive schedule of seminars by leading experts in this field, the Annual Conference is a prestigious event that provides education and inspiration to hundreds of suffers of all ages, their families, researchers and treatment professionals.

This list below includes just a few ways businesses and individuals can support this life-changing event.


Download a complete program prospectus detailing all opportunities: www.trich.org or call 831-457-1004

Municipal Advertising Sponsor: $3,000 (3 available)
• Logo placement on regional transit advertising for 45 days
• Half-page advertisement in National Conference Catalog
• Half-page advertisement in Conference Program Guide
• Two complimentary registrations to the conference

Poster Session Sponsor: $2,000 (4 available)
This sponsorship provides for travel and registration fees for student presenters.
• Prominent banner placement during Poster Sessions
• Quarter-page advertisement in National Conference Catalog
• Logo placement in Conference Program Guide

Exhibitor Table: $650 Commerical, $450 Non-profit
Your Exhibitor’s Registration Includes:
• At least one registration to the Annual Conference
• Exhibit Space for duration of Conference weekend
• Logo placement in monthly emails to 16,000 subscribers.
• Link to your website, and identification as a sponsor on TLC’s website
• 8,000 social media followers
• 16,000 email subscribers
• 45,000 new web visitors monthly

Opportunities for Exposure:
• At least one registration to the Annual Conference
• 10% discount extended to additional registrants

Sponsorships may include:
• Advertising in the National Conference Catalog and/or the Conference Agenda
• Logo and link in monthly emails to 16,000 subscribers.
• Recognition as a sponsor on TLC’s website
• Exhibit Space for duration of Conference weekend
• At least one registration to the Annual Conference

Custom Sponsorship
Have another idea on how you or your business can participate? Would like to sponsor at a level not listed? We’ll work with you to customize a sponsorship tailored to meet your needs and marketing objectives. Just give us a call!

Scholarship Program
Make a difference with your tax-deductible donation to TLC’s Scholarship Program! 100% of each scholarship fund donation goes toward reducing the cost of registration for children and adults who would otherwise not be able to attend this life-changing event. Donate online: www.trich.org or contact the office for more information.

TLC has a reputation for making a big difference on a small budget. Your support of this program will enable TLC’s life-changing resources to reach exponentially more people who feel alone, ashamed, and helpless.

For more information contact Leslie Lee
831-457-1004 or leslie@trich.org
Each case should be assessed individually to identify potential issues relevant in that family setting.

Studies for TTM at Harvard. A major goal of the Timothy Fund is to provide many promising directions for subsequent investigations into the nature of existing family environment scales or to understand family environment issues are complex.

Thus, our findings imply that the family environment issues we identified in families of adolescents with TTM differ on psychological characteristics and parenting stress from the parents of teens without TTM. We studied only the mothers of adolescents with TTM, since few fathers agreed to participate in our study. These mothers reported more anxiety and depression when compared to the mothers of teens without TTM, though overall symptom severity was not very high for both groups. Mothers of TTM teens reported more impairment on several anxiety scales (experience of anxiety feelings, internal supervision, and a lack of control in their adolescent). There was a tendency for mothers of TTM teens to report less independence in decision-making and less self-sufficiency and assertiveness among family members when compared to control teens. There was also a trend for adolescents with TTM to report more family role problems than did control teens.

An additional study question examined whether other psychological symptoms occurred more in adolescents with TTM and whether these additional symptoms contributed to difficulty in the family environment. First, we observed that youth with TTM met criteria for OCD, generalized anxiety, social phobia and major depressive disorder more often than control teens. Thus, given these findings, we examined whether family dysfunction reported by TTM youth was due to these other psychological problems.

We did not find any differences in the family environment when we compared those only with TTM and control teens without current depressive or anxiety symptoms. However, greater impairment in the quality of family relationships, as well as less family support, was reported by TTM youths without lifetime depression or anxiety diagnoses when compared to control adolescents without lifetime depression or anxiety. TTM youth with current depression or anxiety symptoms also reported more conflict and less independence than teens with TTM and no depressive or anxiety symptoms. Finally, it did not seem that additional psychological symptoms impacted the relationship between family difficulties and TTM severity and distress since these correlations occurred even in those pullers without anxiety and depression. Thus, it appears that these additional psychological symptoms do not seem to be related to the difficulties reported in the family environment and those family difficulties appear to be related mainly to hair pulling.

Next, for our second study goal, we looked at whether parents of teens with TTM differ on psychological characteristics and parenting stress from the parents of teens without TTM. We studied only the mothers of adolescents with TTM, since few fathers agreed to participate in our study. These mothers reported more anxiety and depression when compared to the mothers of teens without TTM. Mothers of TTM teens also reported more problems with moodiness, social isolation, antisocial behavior and a lack of motivation in their adolescent. There was a tendency for mothers of TTM teens to report more restriction of their life activities, more difficulties with their relationship with their spouse/partner, more social alienation and more feelings of incompetence and/or guilt. However, once again, while these were different between moms of TTM youth and moms of controls, the scores were still in the normal range, implying that moms of TTM youth, while having higher scores that moms of controls, were not extremely different than would be expected.

Our third goal was to examine whether the perception of the family environment by youth with TTM correlated with the severity of their hair pulling. What we found was different from what we had expected. Scores on those family environment variables which differed between teens with TTM and controls did not correlate with greater TTM severity. For example, report of more conflict in the family environment by the youth hair pullers was not related to greater hair pulling severity. However, distress related to hair pulling was correlated with greater reported conflict and less family support. In addition, reduced family cohesion was related to greater distress and severity. There was also a trend for greater enthusiasm on control in the family to be related to greater pulling severity. Similarly, there was a trend for adolescent perceptions of responsibility in the family to be related to hair pulling distress. Strong correlations were observed between pulling severity and several areas not previously shown to differ between groups (e.g., effective expression, task accomplishment, involvement and values and norms). Greater hair pulling distress was also correlated with more difficulty in the ability of the family to achieve specific tasks and objectives.

And finally, our fourth goal was to examine whether parents and their adolescents with TTM agree in their assessments of the family environment. What we observed was that the ratings by adolescents on depression and disturbance in the family were more in agreement than were the ratings by mothers. Overall, TTM youth rated the family environment as more problematic than did their mothers.

Discussion
So what are the implications of these findings if you or your family member has TTM? The first take-home message is that TTM family environment issues are complex. As shown above, family variables that differ between groups are not necessarily those that correlate with pulling severity and distress. Additionally, some of the family environment effects may be subtle, such as group differences between TTM youth and control mothers on clinical characteristics, despite all scores for both the groups within the normal range. It may also be the case that the interaction between the youth hair puller and the environment may be more important than the environment alone. It is possible that the family environment differences did exist, more dysfunction was reported in the TTM vs. control families. When correlations did occur between family functioning and pulling severity or distress, worse pulling severity and distress were always correlated with greater impairment on family environment measures.

Several points deserve mention. First, research findings reflect average scores across many participants and may not always be relevant to the individual case. Thus, each case should be assessed individually to identify potential issues relevant in that family setting. Our findings above, however, highlight specific family dynamics that should be explored. Secondly, this is a cross-sectional study conducted at one point in time (rather than a longitudinal study conducted over many time points). Thus, it is impossible to know if the family environment issues we identified are causative (and occurred prior to the development of the hair pulling), consequential (and occurred after the onset of the hair pulling) or independent from the hair pulling per se (and occurring at the same time as the pulling but are unrelated to it). It also may be the case that our failure to identify specific family environment variables as we had predicted may be due to limitations in the nature of existing family environment scales or to under-reporting of problems by participants. Regardless, this study and the first large-sample study of TTM family environment with matched controls and validated assessment instruments. Thus, our findings provide many promising directions for subsequent investigations in the future.

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Continued from page 1

Dr. Keuthen has pioneered considerable research in trichotillomania, skin picking, body dysmorphic disorder, and OCD, and authored many scholarly research papers and chapters. She has been involved in both pharmacological and cognitive-behavioral treatment outcome studies of BFRBs. In addition, she has been instrumental in the development and validation of numerous assessment instruments for both trichotillomania and skin picking disorder. Dr. Keuthen is the author of the popular book Help for Hairpullers.
In my world, good grounding equals con-six children – or various configurations of care from others, this is the integral part of the family well-being that surrounds it emotionally. Feeling deeply connected (in a safe way) to its sense of being an integral part of the rod and the soil that surrounds it. Grounding for a human child feel strongly that BFRBs arise to help protect the child from worse body in an attempt to soothe, or “ground.” Believe it or not, I personally and unaware of “how to ground,” they will generally turn to the this charge. A child that is neurologically hypersensitive in certain ground connection; an ungrounded lightning rod cannot dissipate Here’s a metaphor that might help you understand my thoughts: In 1990, when first asked to explain my views on hair pulling, I make full sense to an adult! We are ALL products of our upbringing, sense to the child or adolescent, causing even more discomfort! I stand by my statement! That said, I do know many wonderful (with or without this process together, and no one is completely independent. In summation, what I get out of this study is this: we are all in this process together, and no one is completely independent. It is not solely my parent’s “fault” that I developed BFRBs. I don’t cater to the notion of blame as we are looking at the systems they exist in? It says to me that something is out of alignment; there is disarray; discordance; unmet needs that need to be addressed. I also see them as a primal attempt of the individual nervous system to diffuse, placi-ate, and soothe a distressed consciousness that is not able to easily process too much of a disjointed emotive “load” picked up from the environment. In 1990, when first asked to explain my views on hair pulling, I thought about the following question, “Tuch is the behavioral manifestation / physiological translation of a neuro-emotional charge.” Here’s a metaphor that might help you understand my thoughts: a lighting rod is used to dissipate a lightning strike through its ground connection; an ungrounded lightning rod cannot dissipate this charge. A child that is neurologically hypersensitive in certain domains is looking at what the needs are, and unaware of “how to ground,” they will generally turn to the body in an attempt to soothe, or “ground.” Believe it or not, I personally feel strongly that BFRBs arise to help protect the child from worst damage that can come from the developmental ability to identify what is happening to them neurologically, i.e., picking up too much of a “load” from environmental discordant factors. Grounding for a lighting rod is a complex interaction between the rod and the soil that surrounds it. Grounding for a human child is feeling deeply connected to its body in a way that makes it an integral part of the family well-being that surrounds it emotion-ally. Whether the family is one parent, one child – or two parents, six children – or various configurations of care from others, this is the “family” for the child. In my world, good grounding equals con-necting in a way that energy flows appropriately and safely. Feel-ing NOT connected (or not “seen”) in some intrinsic way within the family structure is disrupting, and a linkage is made by turning behaviorally inward to filter or diminish this sense of disconnection. Then we have the perfect situation! A physical problem Fix it, but only on the outside! Stopping the behavior is not good enough; that is just the tip of the iceberg. There is inside work, also.

The human nervous system is extraordinary; when needs arise it’s a first resort to try to attempt to address that need. What is more useful than a BFRB for ramping down, ramping up, distracting, soothing, diverting, defocusing, and ultimately “buffering” awareness? From my perspective the problem is this: it is a primal response; rather blind in terms of our current social culture, with no awareness of its collateral damage. In essence, our oldest brain areas are activating far below our conscious control, in an attempt to “regulate” or modulate experience.

This study was funded by a dear friend of mine who has been a member of TLC for 20 years, and who has been a major force in moving research in this field forward. This study is important, and I cannot thank my dear friend enough for daring to fund a study looking deeply at the TTM family environment! I don’t know about any of you, but I have never met a family (with or without a BFRB) that I would say was “completely well and healthy in all aspects.” Yes, I will own that I am highly opinionated, certainly. But I stand by my statement! That said, I do know many wonderful families that are highly functional, as well as quite a number that are sadly profoundly dysfunctional! However, it seems to me most of us (and our families) fall somewhere in between, generally experiencing a wide spectrum of various interpersonal interactions, ranging from outright fear, chaos and conflict, to delightful fun and secure, warm relationships.

Show me the dividing line between Mind and Body. Show me proof that “it’s all in your head” or “it’s just your genes.” Nope. Life doesn’t work that way!

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Executive Director's Report

Jennifer Raikes
Los Angeles, CA
Jennifer@trich.org

Dear Friends,

FLASHBACK to spring 2008…

It was the go-go 00’s, McCain and Obama were debating, “Mad Men” was all the rage, and … ok, I had a newborn baby and don’t pretend to remember much! But in that year of hope and change, TLC’s Board, staff and membership took time out to think hard about our mission and how best to fulfill it in the coming five years.

Then, as now, the fundamental problems our community faces were clear: the shame, hopelessness and isolation that comes from public ignorance about BFRBs, a desperate scarcity of treatment providers, and too few effective treatments.

At the time, we perceived another area that demanded attention: “identity.” We were struggling with a number of aspects of our identity. From the less-than-ideal name “trichotillomania” to its classification and diagnostic criteria: the very identity of the disorder was causing confusion for clinicians and researchers, and hurting our cause.

Most importantly, we had recently awakened to the great prevalence and impact of Skin Picking Disorder and realized that TLC needed to expand our mission to fully serve skin pickers, too – and to adjust our identity so that pickers would feel welcome.

Together, we created a thoughtful and ambitious strategic plan for our organization’s priorities and programs through 2013. We set challenging goals: to vigorously collect data for a new Genetics Biobank, to change the classification and name of trichotillomania and advocate for skin picking in the DSM, and to double and triple the reach of our online support groups.

And, of course, before the ink was even dry, the Great Recession hit. The recession impacted TLC, as it did the rest of the world. But thanks to YOU, our members, we made it through – and were able to grow our programs and services even in the hardest years.

The achievements you made possible over the past five years are worth celebrating! We met or surpassed most of the goals we set. Pat yourself on the back as we review the progress of our last five years…

Identity

- Thanks to the TLC community’s 5-year effort, Skin Picking Disorder is an official disorder in the DSM-5!
- TLC has twice as many skin picker members – and the skin picking community is growing stronger every day.
- Trichotillomania (hair pulling disorder) now has a choice of names, and more accurate classification and diagnostic criteria.
- The identity of hair pulling and skin picking disorders as closely-related Body-Focused Repetitive Behaviors (BFRBs) is taking hold in our community and in the scientific literature.

Research

- Our Research Consortium met its 5-year goal of including 400 subjects in TLC’s Genetics Biobank. This crucial resource – DNA, cell lines and clinical data – will now be freely available to researchers around the world.
- Studies led by TLC’s Scientific Advisory Board members have brought new, effective treatment options into our arsenal: from N-Acetylcysteine to Dialectical Behavior Therapy.
- We tripled our total funding of research compared to the previous five years.
- We created scholarships and a research poster session at our Conference to attract medical students and young researchers to our Conference – and encourage future careers in this field.

Treatment & Recovery

- TLC published the “Expert Consensus Treatment Guidelines” to educate doctors around the world about current Best Practice treatments. Since 2010, these guidelines have been downloaded 68,411 times and we’ve mailed them to more than 15,000 doctors.
- The number of clinicians listed in our treatment referral database has doubled – giving access to knowledgeable treatment providers to many more pickers and pullers.
- TLC trained more than 90 clinicians at our intensive Professional Training Institute (PTI).
- To bring this training to more providers, we launched the “Virtual PTI” DVD program – an additional 85 clinicians have now completed their VPTI certificate.

Outreach

- With your help, targeted Outreach Campaigns have reached tens of thousands of pediatricians, behavior therapists, and school counselors with information and specialized online resources.
- Monthly visitors to Trich.org have doubled to 45,000 unique visitors a month.
- Participation in TLC online recovery communities tripled!
- In 2012, we launched our fast-growing Webinar series – bringing world experts on everything from mindfulness to neurobiological research straight to you.
- And, of course, we continued our events, website, email and personal phone support – and added a thriving Facebook page and Twitter, too.

These successes are not just statistics. Tens of thousands more people know they are not alone, can find a good local doctor, get an accurate diagnosis, and achieve recovery with better treatments.

Shame is lifting. Today, there is a fast-growing community of BFRB advocates – pullers and pickers speaking out in their communities, self-publishing books and blogs and videos, sharing our stories like never before.

The majority of new calls and emails we get at the TLC office are now from parents whose children have only recently started pulling or picking – and who will never have to experience the total isolation of the recent past.

But not much more than twenty years ago, there were NONE. And five years ago, there were only about a hundred.

Let’s keep accelerating our pace – it’s a steep climb but we are only getting stronger.

In our next issue of In Touch, I’ll share the Bold Steps we have mapped out to move us faster up the mountain. Great thanks to the many Members who contributed ideas and opinions to our strategic planning process this year.

With love and gratitude,
Jennifer Raikes

With TLC Board Member Brian Haslam, Mrs. North Carolina 2013 (and TLC Awareness Ambassador) Jaisie Sanctis shared her trich story with attendees of the 2013 Cityworks User Conference.

It is important to recognize and celebrate our progress, because the needs of our community remain profound – and can feel overwhelming. As we turned our attention this year to creating TLC’s next strategic plan, our community faces many of the same basic needs and challenges:

Even the best treatment approaches fail to help many. Most pullers and pickers still suffer alone, without accurate information or support.

There are still only a few hundred experienced BFRB treatment providers in the world.

But not much more than twenty years ago, there were NONE. And five years ago, there were only about a hundred.

P.S. That newborn baby of 2008 – she now knows how to pronounce “trichotillomania” and her little sister does, too! Municipal bus ads have run in San Francisco, Chicago and New York City, educating tens of thousands of people about BFRBs.
Why I am a TLC Member

When I first began pulling the hair from my head, more than 30 years ago, there wasn’t a doctor in my hometown in Iowa who knew why I was pulling. My parents didn’t take me to a therapist. I assume back then, no therapist would have been able to help me anyway. I added the pulling of my eyelashes and eyebrows when I was about 12 years old. No one tried to help me. Kids and siblings made fun of me. My parents didn’t know what to do. I didn’t know what was wrong with me.

I found out about Trich from a pamphlet on a table at the student health center where I went to college. I remember being so excited to find there is a NAME for what I have and there are other people who do it. I had never met anyone else who pulled. I am sorry to say this, but it felt so good to know I wasn’t alone. I wasn’t weird. And there were resources available to help me stop pulling!

Since I found that pamphlet, I have stopped pulling the hair from my head. I have gone to a weekend gathering that TLC held. And doctors and counselors have heard of Trich and for those who didn’t know what it was, I made sure to pass on the information I had.

I donate to the TLC organization to help pay for the research, weekend workshops, etc., so that TLC can get the word out to doctors, therapists, counselors, parents, siblings, and those who suffer from Trich. It’s my way of helping the resources that I didn’t have when I began pulling.

Thank you, TLC!!

Darcy
San Diego, CA

Working together, we will find more effective treatment, and an eventual cure. Thank you for your continued support.

Visionaries Circle

☐ $25,000
☐ $10,000
☐ $5,000
☐ $1,000
☐ $500
☐ $_______________
☐ $_________/month

☐ Please direct my donation to TLC Research Programs.

☐ I would like to make a gift of stock to TLC. Please contact me.

☐ I am including TLC in my estate plans.

☐ My company will match my gift.

My donation is in honor of: _________________________________

Your Name:__________________________________________________________________

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Please select a payment method:

☐ Check or money order enclosed, made out to TLC (US funds only)

☐ Charge my credit card. Amount to be charged: _________________________________

Card number:________________________________________________________________

Exp. Date:_____________________________CV code _______________________________

(from the back of the card. American Express users, please provide the 4-digit number from the front of the card)

Cardholder's Name: ___________________________________________________________

Signature:____________________________________________________________________

Thank you for being part of the solution.

TLC is a 501(c)(3) tax-exempt organization and all contributions are tax-deductible. Our TAX ID number is 77-0266587.

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