A Family Study of Trichotillomania and Chronic Hair Pulling

Nancy J. Keuthen, PhD
Erin M. Altenburger, MA
David Pauls, PhD

In the last issue of InTouch, we reported our findings on the role of family environment in trichotillomania (TTM). In this same study, we also examined the relationship between TTM and chronic hair pulling with other obsessive-compulsive spectrum disorders (OCD and skin picking) to explore possible pulling “phenotypes” (clinical presentations). This article will discuss our findings on whether or not TTM and chronic hair pulling are transmitted within families (Keuthen, Altenburger & Pauls, 2014).

There has been limited research on genetics and TTM, however two studies identified possible “candidate” genes for pulling, though none of these findings have been replicated. A twin study (Novak et al., 2009) reported high heritability rates for hair pulling by comparing the rates of agreement (“concordance”) for occurrence of hair pulling in monozygotic twins (where one egg is shared with identical genetic material) and dizygotic twins (where two eggs are involved and only 50% of genetic material is shared). Higher concordance rates were reported for hair pulling in the monozygotic vs. dizygotic twins suggesting a role for genetics in the etiology of this disorder. Unfortunately, the small sample sizes in this study somewhat limit its interpretation. There was also one early family study of TTM with direct interviews of all participants but it failed to demonstrate familial transmission of TTM. Failure to find significance in this study was likely due to inadequate sample sizes.

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BFRBs as Impulse Control Disorders

In the DSM IV-TR (the old version), trichotillomania was listed as an Impulse Control Disorder along with pathological gambling, pyromania, and kleptomania, while skin picking was not even listed as a disorder and was often classified as an Impulse Control Disorder Not Otherwise Specified. Aside from being grouped with disorders that are seemingly unrelated and undesirable, this Impulse Control classification did have some merit. The word impulsive is defined as “doing things or tending to do things suddenly and without careful thought: acting or tending to act on impulse” (Webster, 2013).

In a way, this is a good description for many people who pull and pick, as the behavior seems to be done without regard for or careful thought about the negative consequences. For some people, pulling and picking seem to happen completely outside of one’s awareness and/or the behavior is done as an almost immediate reaction to either an internal or external trigger (e.g., feeling worried, procrastinating, watching TV, driving, working on the computer, etc.). When the trigger is present, so is the behavior. However, although this describes most people with a BFRB at least some of the time, it does not describe everyone who pulls and picks. Continued on page 6

Obsessive? Compulsive? Impulsive?
Understanding the Complex Nature of Hair Pulling and Skin Picking

Suzanne Mouton-Odum, PhD
TLC Scientific Advisory Board Member
Houston, TX

Trichotillomania (hair pulling) and Excoriation Disorder (skin picking) are often unofficially referred to as Body Focused Repetitive Behaviors (BFRBs). Other BFRBs include nail biting, nail picking, cuticle picking, lip biting, cheek biting, knuckle cracking, and tooth grinding. Until recently, hair pulling and skin picking have not had a good home in the DSM (Diagnostic and Statistical Manual for Mental Disorders), which is the encyclopedia for mental health disorders. Although it is rather easy to describe these behaviors, it is not so easy to describe how they “fit in” with respect to other related behaviors. This article will discuss how hair pulling and skin picking disorders have been classified in the past, how they are classified now, and how the classification impacts treatment decisions for both the people who suffer with these disorders and for mental health professionals.

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Inside this issue:

- Upcoming Events
- Strategic Plan Update
- New Support Groups
- Director’s Report

and more...
Upcoming Webinars
Stay tuned for more info!
April: Due to the conference, we will not be hosting a webinar in April.
Currently in the works:
Knowledge is Power: Learning to Recognize a Co-Occurring Disorder with Marla Deibler, PsyD
Jenni's Story: One Girl's Battle and Triumph Over the Trich Monster with Scott Granet, LCSW

Toronto One-Day Workshop
Understanding BFRBS: Treatment, Research & Recovery Tools for Body-Focused Repetitive Behaviors (Hair Pulling, Skin Picking and Related Behaviors) at the Holiday Inn Downtown Centre with Jon Grant, MD, JD, MPH
Peggy M.A. Richter, MD, FRCP
Steven Selchen, MD, MSt, FRCP
Mark Sinyor, MSc, MD, FRCP
Sarah Robertson, Canadian BFRB Support Network and Jennifer Raikes, TLC Executive Director
TLC hosts leading BFRB treatment providers Dr. Jon Grant, Dr. Peggy Richter, Dr. Steven Selchen, and Dr. Mark Sinyor for a day-long event focused on sharing the most recent advances in treatment, research and recovery tools for these behaviors. The Canadian BFRB Support Network will present on developing local resources and support, a crucial component to long-term recovery.
Review the program agenda and register online: tlc214.eventbrite.com

TLC Annual Conference
SAVE THE DATE!
April 25-27, 2014. Los Angeles, CA
TLC is thrilled to be bringing the 21st Annual Conference back to Los Angeles! Please mark your calendars now, and stay tuned for information on how you can get involved in the largest gathering for BFRBs in the world!
Find out more about any of these events on our website: www.trich.org or by calling 831-457-1004.

TLC Event Calendar

Annual Conference on Hair Pulling & Skin Picking Disorders
April 25-27, 2014 · Los Angeles, CA
· Learn Effective Treatment Strategies
· Share the Latest Research
· Develop Self-Help Tools
· Cultivate Support & Networking Contacts
· For adults, kids, parents & treatment providers
Register before March 25 and SAVE up to $75/person!

Build your unique program of education and recovery from a comprehensive schedule of expert-led seminars on treatment, research, self-help, and parenting strategies. The world’s most experienced clinicians, researchers, and other members of our community will share the latest research, outline effective treatment strategies, and provide take-home resources. Make support and networking contacts and learn real tools for recovery.

Who Should Attend?
People of all ages who live with pulling, picking and related behaviors, their families and loved ones, as well as clinicians looking to improve their strategies for treating these disorders. Special programs offered for younger children, teens, parents and adults with trichotillomania or skin picking disorder.

Why Should You Attend?
· Over 60 workshops, symposiums and presentations covering topics from the latest treatment approaches to self-help strategies
· Networking and support-building opportunities with others who suffer from these disorders
· Accessibility to clinicians and researchers who KNOW trich and skin picking
· Inspiration from stories of triumph and recovery and the knowledge that you are not alone!

Conference Highlights:
Learn about the BPM, a groundbreaking research initiative that could lead to dramatically improved treatment options and remission rates for all who live with hair pulling and skin picking disorders. Don’t miss the formal launch of this exciting campaign!

Keynote Address: Dr. Jon Grant is a pioneer of research into treatment for skin picking and hair pulling disorders. In his keynote address on Saturday, Dr. Grant will highlight what BFRB research has taught us thus far, what issues lie in the way of treatment progress, and what we can do, as a community, to propel research forward.

Trichster Documentary: Sneak Preview
Here at TLC, we are so excited for the release of the documentary film, Trichster, we just had to ask the filmmakers to give us a teaser at the conference. Attendees will have special access to a sneak preview hosted by the film’s director, Jillian Corsie, on Saturday, April 26.

Register online: tlc214.eventbrite.com

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Text deadline next issue: May 5, 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.

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.

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**New Support Groups**

**California: Berkeley**
This is a weekly peer support group for adults 17 and older who have hair pulling and/or skin picking disorders. (Friends and family do not accompany members.)

For more information, join the email group by sending an email to east-bay-support-group@googlegroups.com. Or call or email Amy Curcio: 516-672-3137
groupeastbay@gmail.com

**California: Mountain View / South Bay Area**
A structured, biweekly support group for hair pullers, skin pickers and support persons of all ages. This group fosters a safe, supportive atmosphere to meet others that can help with the acceptance, management of and recovery from BFRBs.

**Meet 1st and 3rd Wednesdays, 6:45-8:00 pm**
For more information, contact Kelsey at 832-233-2071 or kshogren@gmail.com

**California: North Lake Tahoe / Truckee**
This is a peer support group for hair pullers and/or skin pickers of all ages. Meets last Wednesday of each month, date TBA. For more information, contact Tina: 775-843-3337 / tinabina3325@gmail.com

**Kansas: Overland Park**
Peer support group for adult skin pickers and/or hair pullers.
**Meets 2nd Monday of the month 6:30-8:00 pm starting March 10.** For more information, contact Trisha: 913-593-4898 or trisha6270@gmail.com

**Tennessee: Nashville Pullers Unite**
Nashville Pullers Unite is a trichotillomania/skin picking support group open to adult hair pullers and skin pickers 18+. Whether you are on the road to recovery or aspire to be, we invite you to join us and share your struggles and achievements among friends. Join our Facebook group or email us for more information on how you can get involved.

Contact Sam for more information
email: trichnashville@gmail.com
https://facebook.com/groups/153154714895643

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**Other News from the Office**

**Habla Espanol?**
The TLC website has seen a dramatic increase in visitors whose native language is Spanish; as many as 6% of our site visitors speak Spanish -- that's over 4000 people! Kelly, TLC's Program Assistant, has translated many of our basic informational emails for adult sufferers, parents and young adults. And, thanks to several volunteers, the most popular TLC articles are translated...but we need more!

**Translation assistance for many other languages is also needed. If you are an experienced translator and would like to volunteer your services, please contact kelly@trich.org**

**New App from the Makers of Stoppulling / Stoppicking.com**
PullFree is a mobile app currently available at the Apple App store that was developed by leading experts in the treatment of trichotillomania. PullFree is intended for use anytime, anywhere so that tracking your urges, episodes, and victories can be done in "real time."

PullFree will ask you questions about your pulling style, then immediately give you strategies that match your pulling profile. After learning about your profile and strategies, you will start to monitor pulling urges and episodes, and will record what strategies you used in those situations. PullFree tracks your progress, and gives you feedback about your progress, over time.

"PullFree is the most comprehensive mobile app I have found to help manage my struggle with trichotillomania. From detailed tracking of each episode and urge, to customized strategy tips and messages of encouragement, I have found PullFree to be a fun and motivating tool to help drive my recovery process. I recommend it for anyone who suffers from body-focused repetitive behaviors who wants to supplement their therapy or other treatment!"

-Emily S., Austin Trich Support Group

**When you’re a small organization with just five staff, how do you effectively address a disorder that affects millions of people around the world?**

That’s the question TLC’s Board of Directors and staff spent much of 2013 working to answer.

With input from our Membership, we took a careful look at everything that TLC does, and identified those areas where we can have the greatest impact.

We came up with some exciting plans for the next three years! Here are some of our top priorities for 2014-2016:

**Revving Up Research**

**BFRB Precision Medicine Initiative**
TLC is excited to announce the creation of a groundbreaking research initiative we believe could lead to dramatically improved treatment options and remission rates for all who live with hair pulling and skin picking disorders. TLC’s Scientific Advisory Board has collaborated with some of the country’s top researchers and with the National Institute for Mental Health (NIMH) to launch a major, multi-year initiative with the goal of entirely transforming the research landscape for trichotillomania and skin picking. This effort will involve more than 20 leading institutions from across the country, and builds on the groundwork laid by TLC’s successful genetics research collaboration. We will need the dedicated involvement and financial support of the TLC Community to make this initiative a reality. Our formal announcement and unveiling of the campaign is scheduled for this year’s annual conference - so don’t miss it!

**Spotlight on Skin-Picking**

TLC was founded with an initial focus on helping people with hair pulling disorder (trichotillomania). Over the years, we’ve welcomed more and more people into our community who live with skin picking disorder, recognizing that we all share similar challenges and needs. Skin Picking Disorder is at least as common as trich -- and many of us suffer with both. So one of TLC’s priorities from 2014-2016 will be to provide the same level of resources and programs focused on skin picking as we do for hair pulling.

**Help Spread the Word: Calling All TLC Ambassadors!**
Are you a TLC Ambassador? You just might be if you’re willing to speak out on behalf of hair pulling and skin picking disorders. We know that millions are still suffering alone and without basic treatment information about hair pulling and skin picking. So we’re launching an outreach campaign to invite TLC members like YOU to help spread the word that when people are looking for help, they can find the latest research, education and treatment information through TLC.

**More Trained Therapists = More Recovery**

Facebook pages and listserves are great, but sooner or later most people with hair pulling or skin picking disorders need to find a trained clinician who can help guide them on the road to recovery. But far too many communities still don’t have a single trained clinician who understands how to treat these disorders. Over the next three years, TLC will be training even more new clinicians every year, through our own Professional Training Institute as well as with partner organizations who share our concern about these issues. We’ll be expanding access to trainings by creating online courses, and deepening training with opportunities for follow-up supervision by master clinicians.

The TLC Board of Directors and staff are excited to share our vision for these next years, and in the coming months will continue to highlight these priorities and invite you, our members, to become involved.

Together, we can make sure that everyone who struggles with hair pulling or skin picking disorders knows they can turn to TLC as the leading source for education, treatment referrals and research. Together, we can make sure everyone living with these disorders knows that there is HOPE and an incredible community of people to support and encourage them.

Stay tuned! We’ll have more to share and ways to get involved!
For many sufferers, their BFRB is not impulsive, but more intentional and goal-directed. For these folks, pulling and picking achieves another purpose, whether it is to “fix a perceived problem” (e.g., remove those coarse, dark, light, thick hairs; to get all of the “stuff” out of pores; or to make the skin smooth) or to satisfy an urge (e.g., to relieve an itch, to get out and examine a large root, or to feel the texture of the hair as it runs through the fingers or along the face). To really complicate things, most people report that they sometimes engage in their BFRB in the impulsive way (automatic behavior) and at other times in the more intentional way (focused behavior). As a result, this makes classification and understanding of BFRBs really difficult.

**Obsessive-Compulsive and Related Disorders**

The newest revision of the DSM was published in 2013 and had some big changes for hair pulling and skin picking. First, skin picking was listed as a disorder (excoriation disorder), which means that the American Psychiatric Association now acknowledges that this behavior is problematic to the point of requiring treatment, as well as allowing for coverage through insurance.

The diagnostic criteria for excoriation disorder are:

**A.** Recurrent skin picking resulting in skin lesions.

**B.** At some point during the course of the disorder, the skin picking is not attributable to the psychological effects of a substance (e.g., cocaine) or another medical condition (e.g., scabies).

**C.** The skin picking causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

**D.** The skin picking is not attributable to the psychological effects of a substance (e.g., cocaine) or another medical condition (e.g., scabies).

This new DSM-V, hair pulling and skin picking are now categorized with obsessive-compulsive disorder, body dysmorphic disorder, hoarding disorder, substance/medication-induced obsessive-compulsive and related disorder, and obsessive-compulsive and related disorder due to another medical condition (APA, 2013). The chapter on Obsessive-Compulsive and Related Disorders immediately follows the chapter on Anxiety Disorders suggesting that Obsessive-Compulsive and Related Disorders are closely related to Anxiety Disorders, although not classified as such.

Are **Trichotillomania and Excoriation Disorder the Same as OCD?**

Let’s take a look at the similarities and differences between these disorders:

**Similarities**

- They are repetitive, unwanted behaviors
- Sometimes behaviors in both categories are performed to create symmetry or to make things feel “even” or “just right”
- BFRB behaviors and OCD rituals can both occur in response to irrational thoughts or beliefs

**Differences**

- People with OCD hate their rituals, while people with BFRBs really like/enjoy them (they just don’t like the outcome of them)
- In OCD, rituals are performed almost always to reduce anxiety, while BFRBs are sometimes performed to relieve anxiety, but also in response to a variety of internal and external cues (e.g., boredom, excitement, presence of mirrors, etc.)
- In OCD the thoughts center around something “bad” happening if the behavior is not performed while with BFRBs the thoughts are usually about “fixing” a perceived problem
- The treatment of choice for OCD is exposure and response prevention (ERP) while for BFRBs a function-based approach is warranted
- Medications for OCD do not work consistently for BFRBs

Although having some overlap, in looking at the similarities and differences between OCD and BFRBs listed above, it is obvious that the two disorders are not the same; in fact, they share more differences than similarities. In this way, it makes sense that BFRBs have been reclassified as Related Disorders, rather than a part of OCD.

The **risks of treating BFRBs as OCD are few, but significant.** First, if a psychiatrist views hair pulling as the same as OCD, he might prescribe medications for OCD to treat the hair pulling (SSRIs or SNRIs). In cases where a person does not also suffer from depression or anxiety, this is not a good choice. As stated above, the medications for OCD do not typically work for BFRBs. Over time, when patients do not respond positively to a medication (i.e., with a reduction in symptoms), medications may be increased in dosage or additional medications may be added. Over-medicating or improperly medicating can lead to unnecessary side effects, health risks, and frustration for both the patient and the psychiatrist.

If a therapist were to treat hair pulling as OCD, she would simply put the client in a high-risk situation repeatedly and have them not pull.

The same risk for psychiatry is also present for psychology. In viewing BFRBs as the same as OCD, treatment will progress quite differently. Attempting to treat a BFRB without understanding how the BFRB functions in a person’s life is not likely to be successful. This is because good treatment involves a comprehensive assessment of the internal and external triggers that cue a person to pull or pick. Once this is complete, strategies that help a person to alter specific high-risk environments, or cope with unpleasant experiences are then offered. If a therapist were to treat hair pulling as OCD, she would simply put the client in a high-risk situation repeatedly and have them not pull. In other words, she would expose the client to the urges to pull while preventing the response (ERP). This approach can be useful for people with a BFRB, but it is employed later in treatment, only after a person has learned about themselves and their triggers to pull, how to utilize coping strategies effectively, and navigate high-risk situations successfully. The skills in doing exposure at the onset of treatment, prior to any self-examination, is that the patient will not understand the nature and purpose of the pulling behavior, and may become overwhelmed, not know how to resist the urges, and symptoms may actually get worse. Ultimately, the biggest risk is that the patient will withdraw from treatment with a feeling of hopelessness about getting better.

As Charles Mansuetu, PhD, once said, “Hair pulling and OCD are more like distant cousins than brother and sister.” There are some similarities, but some definite differences that set them apart. Classifying BFRBs as Obsessive-Compulsive and Related Disorders makes sense and is an improvement over the previous classification of Impulse Control Disorders. There is another diagnosis, however, that needs further examination and clarification regarding how it relates to BFRBs- body dysmorphic disorder (BDD).

The next section will review the diagnostic criteria for BDD and will examine the similarities and differences between BFRBs and BDD.

**BDD and BFRBs: How are they related?**

BDD is now also classified in the category of Obsessive-Compulsive and Related Disorders. The diagnostic criteria for BDD are as follows:

- A. Preoccupation with perceived defects of flaws in physical appearance that are not observable or appear slight to others.
- B. At some point during the course of the disorder, the individual has performed repetitive behaviors (e.g., mirror checking, excessive grooming, skin picking, reassurance seeking) or mental acts (e.g., comparing his or her appearance to that of others) in response to appearance concerns.
- C. The preoccupation causes clinically significant distress or impairment in social, occupational or other important areas of functioning.
- D. The appearance preoccupation is not better explained by concerns with body fat or weight in an individual whose symptoms meet diagnostic criteria for an eating disorder (APA, 2013).
BDD has some significant overlap with BFRBs that needs examination and discussion. As stated earlier in this article, some people pick and pull in response to triggers that involve “fixing” a perceived problem such as removing the coarse/dark/light/thick hairs, removing the exocutate from a blemish to “help it heal,” removing a scar to restore the skin to a smooth state, or removing large roots to “get them out” of the head. Criteria A and B of BDD describe this almost exactly.

Could hair pulling and skin picking really be BDD? What makes them different? Are they different? The answer is complicated in one aspect and simple in another. Yes, some hair pulling and skin picking have a very BDD feel in that the behaviors occur in response to some offensive aspect of the skin or hair. However, many times the “offensiveness” is not actually in appearance, but in some sensory aspect, such as an offensive tactile sensation (e.g., a rough, uneven, coarse, or somehow unpleasant texture). The criteria for BDD do not mention any sensory experience except for appearance as triggering the repetitive behavior, so these folks who pull and pick in response to tactile sensations fit more accurately in the BFRB category within Obsessive-Compulsive and Related Disorders.

Inclusion of Excoriation Disorder in the DSM-V is probably the most significant achievement for BFRBs in years.

What about the people who do pull and pick in response to the perceived offensive appearance of their hair or skin? Do these people not have trichotillomania or excoriation disorder, but have BDD instead? Here is where I believe the answer is simple. If a person only pulls or picks in response to offensive appearance and never in response to other triggers (e.g., internal triggers such as emotions, cognitions, or sensations; external triggers such as activities, places, or environmental cues; or implements such as tweezers), then the behavior would fit more accurately in the BDD category. Although this does happen, it is rarely the case. Therapists must be well trained and aware of this subtle difference, as there are implications for treatment. If hair pulling and skin picking involve triggers from appearance even some of the time, the therapist should incorporate treatment derived from the BDD literature (e.g., distress tolerance) into the comprehensive, function-based approach.

Conclusion

As stated at the onset of this article, BFRBs are difficult to classify because individuals who suffer with these disorders are unique and oftentimes complex in their presentation, and often do not fit nicely into any one category. However, we have made great strides in the classification of these disorders, which hopefully will reduce confusion and improve treatment options.

First and foremost, inclusion of excoriation disorder in the DSM-V is probably the most significant achievement for BFRBs in years because it legitimizes the behavior as a real problem beyond just a “bad habit.” Second, the switch for BFRBs from Impulse Control Disorders to Obsessive-Compulsive and Related Disorders will hopefully result in a better description and conceptualization of these behaviors and improvements in treatment from both a therapeutic and a pharmacological perspective. Nonetheless, a potential risk in this Obsessive-Compulsive and Related Disorders category is that BFRBs will be treated purely as OCD (both by psychiatry and psychology) and not the complex behaviors that they truly are. Finally, BFRBs are at risk for being misdiagnosed as BDD due to the relatively broad new diagnostic criteria for BDD. Mental health practitioners must be aware of the differences in both diagnosis and treatment of all of these related, but different disorders. Sadly, people with BFRBs often feel misunderstood by both the public in general and even mental health providers specifically. It is timely that we acknowledge the complexity of these behaviors and move away from oversimplifying them. As a result, treatment becomes more complex and able to address the individual needs of each client.

Suzanne Mouton-Odum, PhD, is a psychologist in private practice in Houston, Texas. She has treated people with trich and other BFRBs since 1993, and has been a member of the Trichotillomania Learning Center Scientific Advisory Board since 2001. Dr. Mouton-Odum is author of Guide Hair Pulling Disorder, and has recently joined the faculty of TLC’s Professional Training Institute. She is the owner and lead developer of the only interactive website in treatment for trichotillomania, stoppicking.com, and for skin picking disorders, stoppicking.com.

Family studies investigate familial transmission of a disorder by examining whether the first-degree biological relatives (parents, siblings or children) of individuals with a disorder (“cases”) have higher age-adjusted prevalence rates (“recurrence risk”) for this disorder than the first-degree relatives of individuals without the disorder (“controls”). When disorders recur across generations of the same family, genetic involvement is often quoted. However, it bears mention here that a family study is NOT definitive proof of genetic etiology as similar family environments across generations could hypothetically explain the same result.

In our family study, we found that hair pulling is indeed “familial.” In other words, first-degree relatives of hair pullers are more likely to have hair pulling than are the first-degree relatives of controls who do not pull. Higher recurrence risk for OCD was also reported for the first-degree relatives of hair pullers than the first-degree relatives of controls. While we found higher recurrence risk rates for skin picking in our hair pullers than in our controls, we failed to find higher recurrence risk rates of skin picking in the relatives of hair pullers vs. the relatives of controls, as we had expected. The risk rate for skin picking in the relatives of hair pullers (5.6%) was higher than estimates of population prevalence for skin picking but not significantly different from that of the relatives of controls. This finding could reflect sample size issues such that even a few positive cases in a modest sample could increase recurrence risk. Further, controls were not excluded based on skin picking status; thus, the elevation in skin picking in relatives of controls could possibly be due to skin picking also being familial. Future studies should replicate this analysis in even larger sample studies.

In addition to finding that hair pulling was familial, other analyses suggested that there is a subtype of hair pulling related to OCD that also runs in families. This finding parallels earlier research suggesting both compulsive and impulsive subtypes of hair pulling from responsive patterns on a neurocognitive test. Comparison of our adult hair pullers with and without comorbid OCD indicated that higher anxiety and depressively severe was reported for pullers with comorbid OCD. (Adolescent pullers with and without OCD did not differ.) In addition, the OCD had an early onset (at an average age of slightly over 9 years old) in those pullers with co-occurring OCD. The identification of different pulling phenotypes could have significant implications for treatment. It is commonly reported in treatment outcome studies that only a subset of participants improve. This may be due to the fact that hair pullers with different clinical presentations of pulling and different co-occurring disorders need different treatments. Identification of all hair pulling “phenotypes” may optimize care and make significant improvements in treatment efficacy.

In summary, our study confirmed that hair pulling runs in families, as does OCD when it co-occurs with hair pulling. There appears to be a hair pulling + OCD phenotype that should be further investigated, especially with regard to how the additional OCD symptoms impact treatment outcome. Our findings did not support some of our predictions regarding skin picking and hair pulling and should be repeated in future large-scale studies.


Nancy J. Keutten, PhD, is an Associate Professor of Psychology at Harvard Medical School and staff psychologist at Massachusetts General Hospital, where she serves as Co-Director of the Trichotillomania Clinic and the Chief Psychologist in the OCD Clinic. She is currently Vice-Chair of TLC’s Scientific Advisory Board. Dr. Keutten has pioneered considerable research in trichotillomania, skin picking, body dysmorphic disorder, and OCD, and authored many scholarly research papers and chapters. Dr. Keutten is the author of the popular book Help for Hairpullers.

David Pauls, PhD, was the director of the Psychiatric and Neurodevelopmental Genetics Unit from September 2001 - 2011. Over the past 25 years, his research has focused primarily on the genetics of child neuropsychiatric disorders. Research under his direction has led to a better understanding of the inheritance of Tourette Syndrome, OCD and dyslexia. At the present time he leads an international consortium of investigators devoted to finding genes for Tourette Syndrome and related conditions.
Together We Are Strong! Stories from the TLC Community

Amy
I'm 29 years old and have been pulling out and eating my hair since I was 9 and hiding it because of the embarrassment. Today I showed my fiancé and best friends because I was so tired of worrying if I'd have a spot showing. I wore the same hairstyle for almost 10 years trying to hide it. My friends and fiancé are an inspiration to me because they stood by my side and helped me shave my head.

Raphaele
I'm nearly 43. I've been pulling and picking since late elementary/early middle school. A turning point was being openly able to speak aloud about Trich and speak to hairdressers without freaking out! My advice to others who suffer is to seek help— you are not alone. Seek doctors that are willing to hear you.

Naomi
I was about 20 years of age when I discovered Trich. It was a recognized condition. Until then I felt isolated, ashamed, embarrassed & at times dirty for what I did. I felt the rest of the world was normal whilst I was this strange individual with this unique habit. I didn't even think that anyone else could or would perform the bizarre little rituals that had become such a part of my life.

My advice to others who suffer is YOU ARE NOT ALONE!!! You are not weird or abnormal or any less of a person. You are a normal human being who happens to pull out their hair, that's all. Doesn't make you any less of a person.

Genevieve
I was diagnosed with body dysmorphic disorder (BDD) and obsessive-compulsive disorder in my early teens. By the time I was fifteen, I had developed severe dermatillomania. I would spend hours upon hours locked in the bathroom and tearing the skin on my face and my body to shreds. I missed several days of school due to my condition, and almost didn't graduate from high school. I did make it into college, but the skin picking affected my academic performance so much that I was put on probation my first semester.

I have since found a psychologist who specializes in treating those with skin-picking disorder, and I spent an intense year learning cognitive-behavioral techniques to manage my picking and my overwhelming anxiety. It's taken years and years of breaking down, healing, and getting back up on my feet, but I've refused to put my life on hold. Despite a rocky start to my academic career, I've graduated with my bachelor's degree and I'll have my master's degree in just a few months! It is true what they say; healing is not a destination. It is a journey, and it will last my entire life.

Christine
Focus just on this “one moment” in front of you. What choice will you make at this moment. Now, repeat. Focus on the “next best step” for you. At some point the moments of not pulling begin to string together like a strand of pearls. Success is defined by the choice I make right this moment. I am NOT my Trich... I am me.

Dear Friend,

People who contact TLC are often scared and desperate. Skin Picking, Hair Pulling, BFRBs, are not yet household words. When the pulling and picking begin, most of us don't know what is going on… what is happening to me? My child? What can I do?

Still, today, many people find TLC only after long years coping alone. We are reminded each week of the insidious effect a BFRB can have on a person's life when experienced without hope or support.

"I've suffered from trichotillomania for almost 20 years now. No one in my family understands… I hope it will go away one day… I've let it ruin a large part of my life already."

"I want to know what it feels like with a head full of hair and never have the urge. I would love to know what it felt like to never want to pull it. I lived a horrible hellish life with this disease. I went through hardships with school, and other classmates. I would rather die before my kid ever went through stuff like that."

"I've been really desperate for a solution. My skin picking has really crippled me in so many aspects of my life but I can't seem to stop. I hope [TLC] can help."

When someone finds and contacts TLC, a glimmer of hope seems to stop. I hope [TLC] can help.

As discussed in our last issue, our staff and Board spent much of the past year thinking hard about all that TLC does, and all that we need to do to foster recovery for the millions of people struggling with BFRB disorders. In this issue, I'm proud to be sharing a bit about the plans and strategies we will be developing over the next three years.

One immediate way you can contribute is by helping to kindle hope in other pullers and pickers.

In February, we launched the "Strong Together" campaign to build an even more powerful recovery community. Now you can safely and easily share your own strength and healing with others. Please join this campaign – visit www.trich.org/together to submit your own stories, and find inspiration in the words, pictures and videos made by others. We’ve shared a few of these stories on the previous page.

I never knew the power of support until I was surrounded by individuals who share the same struggle.

U ppl r the only hope for ppl like me :)

Turning fear and despair into hope and healing… that is the power of TLC.

With love and gratitude,

Jennifer

New from store.trich.org

Snake Bracelets are Back!  Fiddles  Awareness Bracelets and more!

in touch

Jennifer Raikes
Los Angeles, CA
Jennifer@trich.org

TLC – providing hope and healing since 1991

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With love and gratitude,

Jennifer
I remember the first time I pulled; I was an 8 year old girl home sick with the chicken pox. That 8 year old girl is now a 24 year old woman is still fighting a war with trichotillomania. After a handful of unsuccessful psychiatrists, I knew I needed to find another way to beat trich.

As strange as it is, having trichotillomania has given me a purpose, a life passion. Figuring out everything about this confusing disorder is in my heart what I'm supposed to do. As an introvert with a hint of social anxiety it's been difficult to start taking action within the trich community all alone. If TLC needs any volunteers or possible ideas for future workshops, I would be honored and indefinitely dedicated to help out the Trichotillomania Learning Center.

In April I attended the TLC conference in New Jersey and was moved to the point of tears. For the first time in over 10 years I didn't feel alone. I never knew the power of support until I was surrounded by individuals who share the same struggle. I felt closer and more secure around this community of strangers than any friend and any family member. I can’t thank the TLC staff enough for that beautiful experience, and I can’t wait until I am financially about to donate more than $20 a month to help put an end to this emotionally draining disorder.

Please Donate
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