Early Research Results!
What We Know and What is Still Unknown

The first project of the BPM Initiative set out to combine existing research data from a variety of smaller studies previously conducted by our researchers, enabling collaborative analysis of a much larger data set.

Thanks to TLC members’ support for the BPM Initiative over the past year, Drs. Nancy Keuthen, Jon Grant, Doug Woods, Chris Flessner, Christine Lochner, and Dan Stein have been able to undertake the difficult work of sharing and analyzing data from patients in many smaller studies each had conducted. Altogether, they have examined information from 680 patients, which is by far the largest BFRB data set we have analyzed.

This work is already generating research papers in professional journals, bringing attention to our BPM results from the wider clinical and research community. But even more importantly, these early findings are providing our research team with a fuller picture of what we know – and what we can’t know – from our current data, and therefore how to better design the BPM research protocol to get the answers we need.

TLC’s Conference, held in Dallas, TX, this April, offered attendees the chance to hear directly from the researchers at the frontline of BFRB research about our progress with the BFRB Precision Medicine Initiative, what we have learned so far, and where we are heading. Here is a summary of this exciting early progress as presented by Drs. Jon Grant and Nancy Keuthen in Dallas.

The mission of the BFRB Precision Medicine Initiative is to undertake an unprecedented, in-depth data collection of a large set of BFRB patients – 300 over the next three years. TLC’s BPM researchers will collect clinical and genetic data, family history, neuro-images, and biological markers. This data is expected to help us to pinpoint each person’s BFRB profile, enabling treatment providers to target treatments more precisely, dramatically increasing remission rates over the next seven years.
Upcoming Events

St. Louis, MO One-Day Workshop
Sunday, August 7, 2016, 10am - 5pm
Webster Groves Parks & Recreation, St. Louis, MO
Local treatment providers and support group leaders will lead informational and interactive sessions about:
• Effective treatment approaches for BFRBs
• Behavioral strategies to help reduce picking and pulling
• Coping skills for teens and parents
• Local resources for support and treatment
The workshop is best suited for those (13+) with hair pulling, skin picking, nail biting, and/or other BFRBs, their parents, partners/spouses/support persons, and treatment providers.

Learn more & register at bfrb.org/stl

Charlotte, NC One-Day Workshop
Saturday, October 29, 2016
TLC is headed to Charlotte! Plans are in the works for a one-day workshop for adults and teens affected by BFRBs, parents, loved ones and supporters. We’ll have details posted soon!
Stay tuned to @tlcbfrb on social media or check bfrb.org for more details on this and other upcoming workshops and webinars.

Coming Up
Stay tuned for details on the following events:
BFRB Awareness Week: October 1-7, 2016
New York City Workshop: Date TBA
Houston, TX: Professional Training Institute: Date TBA

2017 Annual Conference
April 21-23
Marriott St. Louis Grand, St. Louis, MO
Save the Date! More information coming soon.
News & Announcements

BFRB Billboard in Times Square

Making Noise in NYC!
Thanks to your support, we’re shouting about body-focused repetitive behaviors (BFRBs) from the rooftops! Each day, more than 50,000 people cross Times Square—that’s at least 1500 people with BFRBs and countless more who know someone who might need help. The advertisement features 30 seconds of images, with the phrase, “Can’t stop picking skin?” or “Can’t stop pulling hair?” The current rotation is 3-7 times per hour, 22 hours per day. View a video of the digital ad playing live: bfrb.org/timessquare.

NYC Support Group Celebrates 20th!

Happy Birthday!
The NYC BFRB Support group celebrates 20 years of support and outreach this year. Group members kicked off the celebration by participating in the annual National Alliance on Mental Illness (NAMI) Awareness walk in New York this past May. The group will host a fundraiser for TLC this summer. Congratulations on 20 years, New York City!

TLC Partners with TheMighty.com

We’re thrilled to announce a new partnership that will bring TLC resources in front of a wide-reaching readership. The TLC Foundation for BFRBs will now have a growing home page on themighty.com; our information and resources will appear in stories related to BFRBs and promoted to themighty.com’s 200 million readers.

The Mighty is a story-based health community focused on improving the lives of people facing disease, disorder, mental illness and disability. More than half of Americans are facing serious health conditions or medical issues. The Mighty publishes real stories about real people facing real challenges - stories that inspire activism and reduce shame.

TLC is dedicated to helping people with body-focused repetitive disorders like trichotillomania and skin picking disorder. With this partnership, we’ll be able to help even more people. We encourage you to submit a story to The Mighty and make your voice heard! Visit themighty.com for more details.

Thank you, Latham & Watkins, LLP!
All of us at The TLC Foundation for BFRBs wish to thank the international law firm Latham & Watkins LLP, for being a friend, supporter, and invaluable resource to this organization and our community. Latham partner and TLC Member Jim Barrall, and his colleagues Tanya Syed and Ghaith Mahmoud have been leading a cross-borders, interdisciplinary team to assist TLC in the process of our name change and developing our new website, providing the highest level of pro bono legal resources.

Prior to this project, Latham & Watkins assisted with the contracts to enable us to establish the first Genetics Repository for BFRBs. Their generous help has enabled TLC to serve our community at a greater capacity than our limited resources would otherwise have allowed. Thank you, Latham & Watkins for being an important partner in TLC’s mission this year!
When Bobbie started a support group near Detroit, MI in 1993, she did not know that Christina Pearson had already founded TLC on the West Coast two years earlier. Like Christina in California, she simply felt determined that she and others with trichotillomania should no longer have to suffer alone.

Bobbie learned from a newspaper article in 1989 that trichotillomania was a disorder – and other people suffered with it, too. At that point she had been pulling her eyelashes for 26 years. She sought help at an OCD and anxiety clinic at the University of Michigan Ann Arbor, and was able to recover.

Empowered by this experience, Bobbie found a meeting space in a local hospital and launched the Detroit support group that she has now run for 23 years.

In recognition of her pioneering work and her decades of service to people with BFRBs, the foundation honored Bobbie with the Christina Pearson Award for outstanding service to the community. Christina presented the award to Bobbie at TLC’s annual conference in April.

“The Board of Directors felt Bobbie was particularly deserving of this award because of her selfless service over the years and her dedication to promoting self-acceptance and recovery,” says Jennifer Raikes.

For her part, Bobbie says she is grateful but a little puzzled by all the fuss.

“I feel that I’m only doing what I have to do—when I got control over trichotillomania 25 years ago, I couldn’t just leave it behind,” says Bobbie. “What would have been the point of 20 years of that suffering if I couldn’t turn it around and use what I’ve learned to help others?”

Bobbie finds meaning in supporting The TLC Foundation for BFRBs because “our kids should not have to have their lives warped by these disorders. I tell the support group members that diseases and disorders like cancer, diabetes, and AIDS receive millions and millions of dollars in donations, but who is going to support trichotillomania if we don’t?”

Bobbie advises people struggling with BFRBs to form an identity separate from the disorder. “In our group, we stress that you are not your [BFRB] and we look for ways to empower ourselves to heal and not feel the shame and anger we turn in on ourselves. You deserve to be happy!”
For several years, a generous TLC member sponsored The Annual Conference Medical Student Scholarship with the goal of encouraging medical students to pursue a career in the field of BFRBs.

Sandra Darling, DO, received the scholarship as a medical student in 2012. Four years later, she is a primary care provider at the Cleveland Clinic Wellness Institute in Ohio, where, in addition to general practice, she specializes in preventive medicine, health, and wellness. She is also a member of TLC’s service provider referral list, and a regular presenter at TLC’s Annual Conferences.

In practice since August 2015, Sandra’s interest in BFRBs developed from her own struggles with skin picking since her early teens.

“I’m in recovery now,” explains Sandra, “but I suffered for over 25 years. The scholarship gave me the opportunity to attend the conferences, which wasn’t possible for me on a medical student’s income. I saw a lot of professionals addressing behavioral health at the conference, but I saw there was a need for a physician to address the dermatological side of this disorder.”

Sandra reached out to TLC so that she could give back to our community by presenting the workshop “Skin Care for Damaged Skin” to teach skin pickers the basic anatomy of skin, its role in our overall health, and how to handle skin conditions that may trigger picking.

Sandra immediately saw the benefits of her participation at the TLC conference in her practice.

“In the short time that I’ve been working as a primary care provider, I’ve seen a few skin pickers already. I treat them with N-acetylcysteine, following Dr. Jon Grant’s recommendations, and then refer them to Behavioral Health within our center, and then, of course, I optimize their health in other ways.”

TLC is grateful to Sandra and the generous donor who made the Annual Conference Medical Student Scholarship possible. That investment in our community has been paid forward exponentially, as Sandra’s patients now have access to the compassion and treatment advice of a knowledgeable provider well-versed in skin picking disorder.
Researchers examined the role of different personality traits in trichotillomania (TTM). Neuroticism is one personality trait in which people are prone to experience negative emotions of anxiety, anger, envy, guilt and worry. They found that each 1-point increase in a neuroticism score resulted in a 10% greater chance of a TTM diagnosis. Higher scores on neuroticism and the personality trait of openness and lower scores on the personality trait of agreeableness were associated with greater hair pulling severity. Also, higher scores on neuroticism was associated with less control over hair pulling and higher scores on neuroticism and lower scores on openness were associated with greater focused pulling.

Researchers also examined whether distinct personality prototypes were present in TTM. Two clusters were identified; cluster 1 had higher scores on neuroticism and lower scores on extraversion, agreeableness and conscientiousness than cluster 2. Those in cluster 1 had more focused pulling and greater depression, anxiety, and stress. Those in cluster 2 had a higher quality of life.

Another trait or emotion that proved to be significantly related to TTM was self-directed anger. Compared to non-pullers, hair pullers reported higher rates of inwardly directed anger and more difficulty controlling that anger. Frequency of inwardly directed anger was significantly correlated with hair pulling severity. Furthermore, inwardly directed anger was a significant predictor of hair pulling severity, even after controlling for current psychiatric comorbidities, accounting for an additional 4.8% of the variance in TTM severity.

Looking forward: Personality factors and strong emotions are often overlooked in current treatment, yet these early analyses show that they may be important clues to possible BFRB subtypes. If treatment can target and address these subtypes, it may enable people with more severe disorders to recover and have a higher quality of life.

Overall, prevalence rates were 3.5% and 5.1% for clinical picking and sub-clinical picking disorder, respectively. Not surprisingly, those with clinical skin picking had more severe picking and greater impairment. Clinical skin pickers were also more likely to have a family history of skin picking. Clinical skin pickers experienced higher levels of perceived stress, greater obsessive compulsive and depressive symptoms, and greater substance use than sub-clinical pickers.

Looking forward: Future research needs to longitudinally examine the relationships (or lack thereof) between clinical and sub-clinical skin picking.

Gender

This early data analysis left us with many unanswered questions about the role of gender in BFRBs. The only notable differences between men and women with trichotillomania were the pulling sites (males with TTM were more likely to pull from their face, arms, and torso) and the fact that men were more likely to suffer from a co-occurring substance use disorder. However, we have limited information on gender differences due to the low rate of men enrolled in these studies.
Looking forward: We hope the larger number of patients studied through the BPM will bring the ability to learn about any important gender differences more accurately.

Co-occurring Disorders

Our researchers found that subjects with both skin picking disorder (SPD) and hair pulling disorder had higher severity of their BFRBs, and responded less robustly to treatment.

Additional research is underway to identify risk factors for TTM and the co-occurrence of other disorders in TTM. One manuscript examining the predictors of comorbid OCD and comorbid SPD in TTM is currently under review for publication. Additional analyses are in progress to predict TTM itself and co-occurring eating disorders in TTM.

Looking forward: We hope work towards being able to predict BFRBs in young patients will ultimately lead us to our highest goal: prevention.

Family History and Environment

77 participants (29.1%) had a first-degree family member with a BFRB and 59 had a first-degree family member with a substance use disorder (22.2%). The amount of time spent picking or pulling per day in the past week was higher among those with a first-degree relative with a substance use disorder.

BPM imaging studies and the larger number of clinical markers that will be collected during the BPM research may help determine if one's family history also has unique biological underpinnings. This might enable clinicians to select different treatments based on family history.

Looking forward: Family history is an important risk factor for any disorder, and understanding it would ease the implementation of precision medicine of BFRBs. What biological markers could be used to pinpoint genetic risk factors? And how can we consider family history more thoroughly in the treatment process? Treating the child of someone with a BFRB early enough could make a difference in ensuring they never develop a BFRB themselves.

Publications


For more information about BPM, contact Jennifer Raikes:
831-457-1004 or
jennifer@bfrb.org
Age at Onset of Trichotillomania
Sarah Redden, BA, University of Chicago

Age at onset has been associated with important clinical differences in a range of mental health disorders. The significance of age at onset of symptoms of trichotillomania (TTM) however, has not previously been investigated due to small samples.

Using the largest sample of individuals with TTM, we sought to understand the significance of age at onset as it relates to hair pulling symptom severity and impairment. Those individuals who started pulling later in life had greater psychosocial dysfunction due to their pulling.

Does Having More Than One BFRB Matter?
Sarah Redden, BA, University of Chicago

Many individuals with TTM also have skin picking disorder (SPD). No research has examined, however, if the co-occurrence of these disorders results in a different clinical presentation or more severe symptoms than when a person only has TTM. We sought to discover the similarities and differences between having TTM and SPD as opposed to just having TTM.

Of the 395 adults with TTM, 57 (14.43%) had co-occurring SPD. In terms of severity measures, those with TTM and SPD had significantly more severe trichotillomania symptoms. Adults with both TTM and SPD were significantly more likely to have current major depressive disorder. Interestingly, psychosocial dysfunction did not significantly differ between groups.

These results suggest that individuals with TTM and co-occurring SPD may have more problematic hair pulling symptoms and depression. Thus, evaluating people for multiple BFRBs may be important to understand the severity of their symptoms and may have treatment implications.

Comparing brain volume and cortical thickness in women with skin picking disorder and trichotillomania
Annerine Roos1, Jon E. Grant2, Jean-Paul Fouche1, Dan J. Stein1, 3, Christine Lochner1

Skin picking disorder (SPD) and trichotillomania (hair pulling disorder, or HPD) significantly overlap in terms of clinical traits. Yet few studies have directly compared structural brain data in these disorders, and evidence suggests that they affect fronto-striatal circuitry.

The aim of this study was to compare volumes of brain regions and cortical thickness in women with SPD and HPD, and determine involvement of fronto-striatal pathways. We hypothesized that fronto-striatal pathways would be implicated in both SPD and HPD.

Participants with SPD had greater volume of the ventral striatum (i.e., accumbens) bilaterally, and reduced cortical thickness in right hemisphere frontal areas, and greater thickness of the cuneus bilaterally compared to HPD and controls. HPD participants had reduced thickness of the right parahippocampal gyrus compared to SPD and controls.

These findings are partially consistent with previous structural work in SPD, and suggest some differences in the neurobiology of SPD and HPD. The more extensive involvement of the ventral striatum in SPD may suggest greater involvement of the reward system, while the

Dr. Annerine Roose, right, discusses brain volume and cortical thickness in TTM patients with Dr. Mary Travis during the poster presentations at the TLC conference.
more extensive involvement of the parahippocampal gyrus in HPD may be consistent with the dissociative symptoms often seen in these patients. Further multi-site collaborations may be useful in achieving larger sample sizes, which may allow for more careful delineation of the neuroanatomy of obsessive-compulsive and related disorders. Since evidence also suggests that treatment targeted at glutamatergic and dopaminergic systems of the accumbens may be beneficial in SPD, this warrants further investigation.

The role of maladaptive cognitions in a skin-picking sample with experiential avoidance as potential mediator Raluca A. Stan and Judith L. Stevenson, Glasgow University

We investigated if beliefs about appearance, shame, and negative evaluation would predict SPD severity. At the time of writing, the analysis of the mediating effect of experiential avoidance is in progress.

In all 250 participants, increased negative beliefs about appearance, shame, and negative evaluation all predicted higher skin-picking severity. An SPD severity score median split revealed that there were significant differences between the high and low groups for beliefs about appearance, shame, and negative evaluation, where the high group scored higher on each measure.

Our preliminary analysis shows that there is a relationship between SP severity and maladaptive thought processes. Our next aim is to discover where experiential avoidance mediates this relationship, as seen in higher TTM severity. Finding such mediation would indicate that targeting experiential avoidance may be effective in decreasing SP severity. Equally important, if experiential avoidance does not act as mediator, it will indicate a difference between SPD and TTM mechanisms, guiding and mobilizing efforts toward a different therapeutic approach.

The effects of “coming out proud” on self-evaluation and self-stigma in trichotillomania Judith L. Stevenson, Pamela Atanasova, University of Glasgow

People with TTM often suffer in silence and do their best to conceal their TTM. Recent literature on “coming out proud” about general mental health indicates positive outcomes in terms of self-evaluation and interaction with others (Corrigan et al., 2010; Rusch et al., 2014). We used this model to explore if TTM who are “out” would demonstrate positive self-evaluations and lower self-stigma compared to TTM “in the closet.”

We investigated if the “out” group would show: (1) lower internalised stigma/negative self-perceptions; (2) lower fear of negative evaluation; (3) higher scores on aspects that counteract self-stigma to aid recovery, and (4) lower discomfort about their hair pulling, compared to “in” TTM.

“Out” TTM exhibited significantly lower scores on stereotype endorsement, alienation, and social withdrawal, compared to “in” TTM, but showed no differences in discrimination experience. Recovery assessment scores revealed that, compared to the “in” group, “out” TTM had higher personal confidence and hope, willingness to ask for help, goal and success orientation, and less domination of symptoms, but no differences in reliance on others. Fear of negative evaluation and overall severity score did not differ, but pulling-related discomfort was significantly lower in the “out” group.

In conclusion, “coming out proud” is advantageous for reducing maladaptive thought processes in TTM. These results can inform both treatment providers and self-reported TTM about the benefits of disclosure for living with TTM.


Despite a growing focus on trichotillomania (TTM), little remains known about its etiology and maintenance. Researchers have proposed emotion regulation (ER) as one model of TTM. This model suggests that hair pulling may function as a maladaptive coping mechanism given difficulty managing negative emotions, such as anger.

In the current study, we sought to provide evidence for the ER model of TTM using measures of anger. Thus, we compared hair pullers versus a normative sample on trait anger, anger expression, and anger control, and explored whether there is a relationship between anger variables and hair pulling severity.

Compared to a normative sample, hair pullers reported significantly more anger expression and significantly less anger control. Additionally, hair pulling severity was positively correlated with anger expression. Furthermore, anger expression was a significant predictor of hair pulling severity, even when controlling for depression and anxiety.

Hair pullers may experience more inwardly directed anger and may have less control over this anger, possibly leading to greater hair pulling severity. These findings provide evidence for the ER model of TTM and underscore the potential importance of addressing ER in the treatment of TTM.
Dear friends,

The weeks have been flying by since I returned from our annual conference in April.

The conference is always an exhilarating experience – if you couldn't be there but want a sense of the amazing energy and love that transforms a mundane hotel into a bustling, vibrant, healing community, you can watch a wonderful highlights reel: bfrb.org/con16.

But what happens next? Is it just back to life as usual? See you next year?

Not for the Cook family!

A month after the Conference, I was delighted to see this message pop up in my Facebook feed: “So proud of Samantha today. This week she decided to share her deepest secret with her friends, and her class.”

12-year-old Samantha Cook came home from the Conference and decided that she did not want to go back to life as usual. She wanted to make change – in herself and in the world.

Samantha has trichotillomania. She has been pulling since 1st grade. Her family contacted TLC immediately for information and referrals, but this was the first Conference they were able to attend.

When Samantha got home from the Conference, she emailed her teacher, Mrs. Bury, the “This is Me” video created by TLC’s Millennial Task Force (bfrb.org/thisisme) and asked if it would be okay if she shared it with the class the next day. Her teacher responded enthusiastically.

Armed with donuts and a TTM Fact Sheet (bfrb.org/FAQs), Sami’s mom Jennifer accompanied her to school the next morning. The teacher began by asking the class to define “rare.” The students brought up jewels and rubies, and that rare things should be cherished and taken care of. She shared the “This Is Me” video and Sami answered her classmates’ questions.

She announced that she planned to cut her hair short the next day, saying, “I’m going to rock it bald if I have to.” She explained that trichotillomania is more common than asthma, yet far less funded in research dollars. We don’t have all the answers yet.

After it was all done, Sami came into the hallway and shared with her mom that she felt relieved and happy she doesn’t have to hide her trich anymore.

But that wasn’t the end of the story. Samantha was a butterfly – flapping her beautiful wings and setting the wind in motion.

The next day, her mom posted, “Wow. We shared the ‘This Is Me’ video and Samantha’s story in her 6th grade class yesterday. This morning, I woke up to this message to her teacher from a student in her class.

Evening Mrs. Bury,

So I was up tonight researching trichotillomania and wanted to make a website addressing it and spreading awareness. I was hoping that as a class we could do a project and maybe even create a video, like say on youtube, about it. Thanks for your time and sorry about bugging you about it this late. –Henry

Letter from the Executive Director

Jennifer Raikes
Los Angeles, CA
Jennifer@bfrb.org
By week’s end, the whole middle school was mobilized. Jennifer posted, “The 7th and 8th grade teachers are going to address their students today. They will handle it like we did: rare, valuable, precious... The teachers are all on board and supportive of Sami.

“My heart is so full right now. In all our dealings about Samantha’s trich, from 1st grade to the beginning of 6th, it’s never been as easy as it is today.”

Sami also took action to help herself control her pulling. As her mom reported, “SHE chose to shave her head today to kick *trichotillomania* to the curb. It was rough watching her go through this, and there were many tears in our dear friend Kelli Hollenbeck’s stylist chair.”

Then, on the last day of the school year, Samantha’s class shared the awareness video they made, with young Henry as the narrator. You can watch it here: bfrb.org/sami.

Jennifer says, “Sami wants to raise awareness of this awful disorder so others don’t live in shame and fear. But no matter how relieved she is, this is still hard for her. She just wants to be a normal 12-year old and be treated the same as everyone else. Our society places a lot of emphasis on hair or lack of it. [Our trich journey] has been mountain top highs and deep valley lows. I love and am so proud of my sweet Sami-lou.”

At TLC, we think a lot about ripple effects. How can we, as a small organization, have the biggest possible impact with our limited resources? How can we as individuals do the same?


Who knows where the wind blows next?

Love,
Jennifer

p.s. Notice all the links to great resources on TLC’s website? Don’t forget to visit bfrb.org and create your Member Log-In today! You’ll have access to all this and a rich archive of hundreds more articles and webinars.
Volunteers Needed

Are you a master at SEO? Have mad database developer skills? A people person who would love to start a support group or moderate online groups? If so, TLC needs you! Contact leslie@bfrb.org. Include in your message what skills you’d like to put to use for the BFRB community. Thank you!

Shop for the Cause

Are you an Amazon.com shopper? If so, visit smile.amazon.com and select The TLC Foundation for BFRBs as your preferred charity. Then, every time you use amazon, start shopping from smile.amazon.com -- and a percentage of your purchase will be donated right back to TLC! Visit the "Get Involved" section of our website for more ways to support TLC with your online purchases.

Share your Story

Have an awareness moment you’d like to share? Is there something you want others with BFRBs to know? Have you learned some helpful coping mechanisms while on your BFRB journey?

Tell us about it! Visit www.bfrb.org/share to post your story, artwork, or poetry. Or, log in to the Member Center to read stories from other community members, like Hannah and her mom, left.

DONATE   VOLUNTEER   CONNECT

Visit bfrb.org or find us on social media @tlcbfrb