Five Things

I Want My Future Partner to Know About Skin Picking

Nico Santamorena, TLC Task Force

Compulsive skin picking isn’t just popping an occasional zit or scratching a bit of dry skin. It is a real disorder characterized by noticeable scarring, marks and damage from digging at perceived flaws. Skin picking disorder, dermatillomania, excoriation disorder — they’re the clinical names for a very misunderstood and often isolating condition, a condition I have.

Almost every day for the past 10 years I have picked at every bump or blemish on my body, causing physical scars as well as mental ones. I have been humiliated, teased, rejected and made to feel less than feminine due to the way my body looks. I have been afraid of relationships, commitment and intimacy. I have been afraid to be honest about my feelings with people and have chosen to distance myself rather than face what I fear will be shame and ridicule. I know that going forward I will have to face my fears, but I feel that whoever I choose to be with needs to realize that the years of accumulated doubt won’t vanish overnight. Here are five things I want my future partner to know about living with dermatillomania:

1. Please don’t make negative comments about my skin.

In the past I have heard everything from “Do you have herpes?” to “Only people who use meth do that.” I have been told I need professional help or that I’m disgusting. I have seen people I consider to be my friends flat-out make fun of someone with bad skin after I have told them about my picking. People I am close to have posted videos to Facebook of a woman being unknowingly filmed while eating the skin from her feet and laughed at her. They make horribly mean comments such as “Wow, what a freak!” and “People like that don’t belong in public.” I consider myself pretty thick-skinned (a little humor never hurt anyone), but comments like the ones above are just hurtful. If you want to ask me about my scars and scabs I’ll be happy to tell you about my dermatillomania, but please don’t be nasty. The same goes for making fun of what you don’t understand.
Upcoming Events

Annual Conference: San Francisco, CA
April 20-22, 2018

There is still time to register for the annual conference! Build your own program of education and recovery from a comprehensive schedule of over 100 expert-led seminars, covering topics like advances in treatment and research, behavioral management, self-help, and emotional healing. Early registration discounts extended until March 15. Learn more at bfrb.org/conference or give us a call: 831-457-1004.

Professional Training Institute: New Jersey
May 18-20, 2018

A three-day intensive training program providing health care professionals with practical training in current cognitive-behavioral treatment approaches for BFRBs. Offers 19 continuing education units and is intended for Psychologists, Psychiatrists, Social Workers, MFTs, Counselors - All levels. Details and registration at bfrb.org/pti.

Outreach Volunteer Training: New Jersey
May 18-20, 2018

Would you like to be a leader in creating resources for BFRBs in your community? This special volunteer training program will provide you with the tools for organizing and educating BFRB resources in your region. Become a youth support group leader, BFRB Educator, or Outreach Ambassador for TLC. Learn more at bfrb.org/getinvolved.

Mindfulness-Based Impulse Reduction for BFRBs with TLC’s Founder, Christina Pearson

Ongoing: visit www.hasacademy.org for details

Live, interactive video classes for adults, teens, children and parents with a focus on BFRB shame reduction, practical living skills, and long-term recovery. Learn the cohesive, strategically adaptive Mindful Living-Skills-Based approach to managing hair pulling and skin picking that has kept Christina Pearson’s recovery on track for years, and gain a heart-centered, experiential interpersonal network "in-the-world-you-live-in" for day-to-day support.

Get tickets and details for these events and more at bfrb.org/events
Community Members Making A Difference

Sustainer’s Circle Donor Profile: Bianca Lyder

Bianca Lyder’s name and face is familiar to many in the trich community. Active with TLC since 2012, Bianca is a salon Service Provider Member of TLC and a presenter at our annual conferences.

A native of Trinidad who immigrated to the U.S. at the age of 12, Bianca has been serving clients with trichotillomania for many years using standard styling, hair extensions, weaving, interlocking, braiding, and non-surgical hair replacement. She has also made it a personal mission to educate other cosmetologists about hair pulling disorder.

Bianca will be an instrumental part of the outreach team that will further educate hair and skin professionals across the country, bringing more awareness and services to our community.

“As a licensed cosmetologist, Bianca understands and knows the stigma associated with any mental health illness in the African-American and other minority communities,” said TLC National Outreach Manager Kaprece James, “so she has taken on the role of serving as our Hair Ambassador to help educate more of the minority communities, as well as the hair and skin professionals in those communities. We are super excited to have Bianca not only as a TLC Service Provider Member, but also as an educator in the community.”

In January 2014, Bianca also chose to become a monthly donor to TLC.

“Working with clients living with trich over the past years has given me a deeper understanding of this hair disorder and the pain that changes lives and lifestyles of individuals,” explained Bianca. “As a Hair Loss Specialist, helping clients to restore their self-esteem and self-confidence is paramount in my work. This propels me to support TLC in every way possible with education and finances to increase resources and support research.”

Bianca is one of a growing number of TLC supporters who are recognized as members of the Sustainers Circle monthly giving club. The contributions of Sustainers Circle members provide the bedrock for ongoing programming and resource expansion.

“Our monthly donors move mountains,” said TLC’s Annual Fund Director Corinne Lightweaver. “We are so grateful to Bianca and the many donors like her who make monthly giving to TLC a top priority. They are truly essential to year-round sustainability of TLC’s services.”

You, too, can join the Sustainers Circle with a monthly gift at whatever amount is right for you. Visit bfrb.org/donate or use the enclosed remittance envelope. Corinne Lightweaver is available at corinne@bfrb.org to answer any questions. Thank you for supporting TLC’s mission!

If you are a Service Provider Member interested in joining the outreach team, please contact Kaprece James at outreach@BFRB.org.
Meet Your New National Outreach Manager

Kaprece James, MPA
National Outreach Manager
The TLC Foundation for BFRBs
Santa Cruz, CA

I am so thrilled to have joined an amazing organization and community that makes a difference in the lives of others every day. The work we do in the BFRB community for people with BFRBs, family members, friends, providers, and leaders couldn’t be possible without each of you. As the new National Outreach Manager, I get the opportunity to further expand TLC’s reach around the country and internationally. Much of this will involve training and developing Outreach Volunteers, BFRB Educators, and providing more support to Support Group Leaders, with the goal of launching our pilot program in selected areas.

Over the last few months, I have had the pleasure to meet and talk with many of you working hard on the ground for TLC and I look further to expanding our work together to help eliminate any stigma or shame associated within our BFRB community.

Throughout the remainder of this year, I will attend events that will increase awareness amongst cosmetologists, educating about what BFRBs are and how they can be a helpful resource within their own community. I am also focused on increasing TLC’s reach into minority populations to provide education on the resources and opportunities we provide here at TLC.

In February, I had the distinct honor of meeting the family of Henrietta Lacks while representing TLC at an outreach event hosted by the African American Community Health Advisory Committee (AACHAC) in the San Francisco Bay Area. For those who don’t know, Henrietta Lacks was an African-American woman whose cells, taken without her knowledge in 1951, became one of the most important tools in medicine. I was inspired meeting over a dozen affected by BFRBs at this event, and I look forward to the thousands of individuals and heroic stories I will get to hear within our community over the next year.

There is a lot of work ahead for me as the National Outreach Manager and of course I can’t accomplish any of it without you. I am looking for volunteers of any age and experience who are ready to create or enhance TLC resources in their own communities. If you are ready to become an Outreach Volunteer, BFRB Educator, or Support Group Leader, I encourage you to attend our 25th Annual Conference, where I will host our first volunteer training. If you can’t make the Annual Conference, there will be several more opportunities as we organize trainings in New Jersey, Atlanta, and other communities in the coming year. For more information, please email me at outreach@bfrb.org.

Let’s get ready to “Take Wing” in 2018.

~Kaprece

Left Photo: Kaprece, second from the left, with members of Henrietta Lacks’ family. Right photo: Kaprece (again on the left), represented TLC and the BFRB community at a seminar designed to bring together the community, health professionals, patient advocates and researchers to learn about clinical trials and their importance among populations of color.
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2. I might have a hard time leaving the house sometimes.

After a tough day, stressful class or sleepless night I might go on a picking frenzy. I will lock myself in the bathroom and dig at every blackhead, scratch off every inch of dry skin, squeeze every bump and lump. When I emerge from the bathroom my face will be bloody and red, my fingers will be raw, and I will feel utterly guilty. If we had plans or I get invited out I will most likely say no. I will be too embarrassed by my appearance and won’t believe you when you tell me no one will notice. I might break down and cry after getting dressed and putting on makeup because I just don’t feel like I look “normal” with copious amounts of foundation and a sweater on in July. Please be kind and please be patient with me.

3. If you see me picking, please don’t tell me to “Just stop!”

When someone points out your flaws it makes you feel bad, doesn’t it? So please don’t point out mine. If you are worried about me or want me to be aware of what I’m doing you can ask me to do something with you to distract me. I would rather you ask me to come cook dinner with you or to go for a walk than be told to stop.

4. I’m afraid of intimacy.

I have only ever been intimate with one person and they knew full well I had scars. Even though I met him through the BFRB community, I was still afraid he would think I was ugly. I am extremely self-conscious of wearing shorts, sleeveless tops, bikinis and being naked because I pick literally everywhere. I have a hard time being comfortable with my body, therefore I have a hard time being comfortable with someone else. If I am shy or apprehensive, please don’t be angry with me or force me out of my comfort zone. I would hope that the person I choose to be intimate with respects my limits and fears and helps guide me through them, rather than pressuring me and humiliating me. If you don’t find my body attractive, please don’t kick me while I’m down and don’t take advantage of my vulnerability and honesty.

“If you are worried about me or want me to be aware of what I’m doing, you can ask me to do something with you to distract me.”

5. Don’t be afraid to learn about my condition.

The best thing you can do for your partner is help and support them. I hope the person I end up with isn’t afraid to ask questions and learn. I hope they want to be a part of my journey to recovery. I want them to ask how I’m doing, to attend support groups with me, and overall to be supportive of me and my decisions. The best thing you can do for someone you love is encourage them and be there for them.

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Call for submissions!
TLC is accepting submissions for this newsletter quarterly and the TLC website. Here’s what we’re looking for:

**Recovery Stories** – personal accounts of one's journey toward recovery. We are looking for stories that detail your personal journey of healing.

**Coming Out Stories** – Maybe you've recently revealed your picking or pulling to your spouse or partner. Or, perhaps you've written an essay and shared it with your classmates. Or, maybe a child or teen would like to write about "coming out" to their parents or peers. You can inspire others with your story of revealing your behaviors to others.

**Treatment and Self-Help Strategies** – Articles that discuss evidence-based treatment, strategies for managing urges, cover-up tools for all BFRBs.

**Poems and Artwork** – Poetry, short essays, drawings and other forms of self-expression.

Send submissions and questions to leslie@bfrb.org.
Dear Friends,

This April will bring TLC’s 25th Annual Conference. I got a bit nostalgic thinking about this and started digging through my files the other day. I have a stash of my Conference programs dating back to 1998. 1998 didn’t used to sound like a long time ago but somehow 20 years have passed.

Our conferences have doubled in size since the early days, and the amount of information we have to share has grown considerably. But the heart of this unique event has not changed. It is about coming together and the profound connections that happen when we do.

Looking back at feedback we received nearly twenty years ago, I see comments that still sum up what we are trying to achieve:

“I just plain loved the conference. It lets me know I’m not alone.”

“This was my first conference and I found myself being a little overwhelmed, but hungry for knowledge and just to talk and listen to people who can relate to me.”

“I love how nice everyone is and how comfortable they made me feel.”

“Thank you so much. I am better equipped to help my daughter.”

“What a relief to be in the company of so many people like me!”

Often, we decide to come to the Conference in search of knowledge – and it delivers. This year, you can be there as the leaders of our BFRB Precision Medicine Initiative report on data from the first 100 subjects in this historic study.

We are offering a special pre-Conference session on Friday morning, the ComB Treatment Intensive for Adults, led by Drs. Marla Deibler and Renae Reinardy.

On Saturday morning, we have a very special keynote speaker, Susan Swedo, M.D., who has been involved in this field since the earliest days of BFRB research. Dr. Swedo began work at the National Institute of Mental Health in the mid-1980s and worked in Dr. Judith Rapoport’s lab as they conducted some of the foundational research into obsessive compulsive disorder. From that work also emerged some of the earliest modern insights into trichotillomania, as people with hair pulling were included in some of the early OCD studies.

“...there is profound healing when we come together face to face. In-person connections are worth the effort.”

Since 1998, Dr. Swedo has been Chief of the Pediatrics & Developmental Neuroscience Branch at the U.S. National Institute of Mental Health. She will be speaking about the ground-breaking work she has done in discovering a subtype of pediatric OCD, in which symptoms are triggered in reaction to streptococcal infection (known by the acronym “PANDAS”), and will discuss what is known – and not yet known – about how PANDAS may relate to some BFRBs.

The conference is a unique chance to share a weekend with the clinicians, researchers, and other leaders in our community – to pull up a chair at the lunch table with Fred Penzel or Ruth Golomb or Jon Grant – and ask them all your treatment questions. You’ll also meet our first “Early Career Award” recipients, rising stars in the BFRB research and treatment field.

I am deeply grateful for the connections that today’s “screens” enable us to make: the ability to anonymously search the term “skin picking” and begin to find answers; the ability to connect in social networks at any time of the
day or night with others who share your experiences; the emerging field of online counseling connecting underserved areas with treatment providers. There is so much help that can be found from the comfort and privacy of your own home.

But the Conference delivers hugs and smiles – and a pool party! Seriously, there is profound healing when we come together face to face. In-person connections are worth the effort. In the words of a Conference attendee in 1998, “I wasn't sure if this was going to be worth the travel, time and money but I was definitely wrong and thankful I came.”

So, that is my hard sell to urge you to join us at the Conference this year. It will be so much better with you there!

But I know that time, travel, or money – or a child’s big soccer match – might make it impossible for you to attend this year. If that is the case, I urge you not to let that stop you from making some face-to-face connections with the TLC community. You might even consider helping to organize a small BFRB event of your own!

TLC is committed to fostering BFRB activism at the local level. In December, Kaprece James joined the TLC staff in the new role of National Outreach Manager, with the mission of supporting our volunteers in building stronger support, treatment, and educational resources in your own towns and cities. If you would like to be more involved as a volunteer, please don’t hesitate to reach out to Kaprece@bfrb.org.

I hope to see you in San Francisco!

With love and gratitude, Jennifer

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**Join the Sustainers Circle: TLC’s Monthly Giving Club!**

As a member of the Sustainers Circle, TLC’s Monthly Giving Club, you can ensure that the Foundation’s programs and services are available to everyone in need. The Sustainers Circle allows donors the convenience of supporting TLC through an automatic monthly gift by credit card or by transfer from their bank account. Signing up is both safe and easy. You can fill out the appropriate section of the enclosed response envelope or sign up on the TLC website. Questions? Contact Corinne Lightweaver, Annual Fund Director, at 831-457-1004 or corinne@bfrb.org.
Have you considered including a gift to TLC in your will?

Naming TLC as a beneficiary in your estate is a surprisingly simple process. It is, however, a decision that can have a positive lasting impact on future generations of family members and millions of people around the world who suffer from BFRBs.

If you (or a parent or grandparent) are preparing a will or working with a financial advisor on your estate plans, please contact us about the possibility of a planned gift in support of the important work of TLC. We will be glad to provide sample language, discuss options for designating your gift and answer any questions you may have. Contact Corinne at corinne@bfrb.org or call 831-457-1004 for more information.

Support TLC When You Shop

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, shop from smile.amazon.com -- a percentage of your purchase will be donated right back to TLC!

Volunteer for Research

Researchers need YOU! Help advance the understanding of body-focused repetitive behaviors by participating in a research study. Volunteer by completing an online survey, or participating at one of the research centers in the U.S. 18 different studies are currently seeking participants. Learn more @ bfrb.org/researchvolunteer.

MINNEAPOLIS, MN
Peer support group for those dealing with hair pulling (trichotillomania), skin picking and/or any other BFRBs. This group meets once a month and provides a safe, non-judgmental environment where people of all ages can find support, encouragement, and helpful tools for their recovery process. mntrichgroup@gmail.com to be added to the private Facebook group.

HOUSTON, TX
A meetup and online support group. Anyone is welcome. Locals are encouraged to participate in events near north Austin, Pflugerville, Hutto and Roundrock area (primary location Hutto). Email Courtney for more details: courtneyporcher@gmail.com www.facebook.com/bfrbhippos

START A SUPPORT GROUP In Your Town
Download helpful resources and tools that will guide you through the process of starting your own group! Learn more at bfrb.org/startagroup.