Over 1000 donors, volunteers, community leaders, researchers, and treatment providers share a vision of a world where body-focused repetitive behaviors are diagnosed quickly, and are not a source of shame. Where information and emotional support are available to people of all ages and their families. Where knowledgeable treatment is available to all people with these disorders, treatments are more effective, and eventually, cures are found.

Each of your individual acts of courage support this vision, transforming your efforts into a collective union for progress.

This year, our community made great progress in TLC’s three areas of work: sharing knowledge, supporting recovery, and finding a cure. As you review your impact and accomplishments this past year on pages 4-8, we hope you feel great pride - you are making a significant difference in people’s lives every single day.

Thank you for being there. ❤️
Upcoming Events

Details for these events and more at bfrb.org/events

Annual Conference on BFRBs

May 2-5, 2019, Chantilly, VA

There is nothing like connecting face-to-face with other people affected by these disorders.

TLC’s Annual Conference on Body-Focused Repetitive Behaviors is the only event of its kind: top BFRB experts, community leaders, and changemakers will guide nearly 500 individuals, families, and treatment providers through a weekend of education, support, and most importantly, healing.

Activities will begin Thursday, May 2 at 6:00 pm, and continue through Sunday, May 5th, at 12:00 pm.

Learn more and sign up at bfrb.org/conference

Interested in supporting this amazing event?
Sign up now to be a conference sponsor, exhibitor, or advertiser!

Partner up with TLC and bring individuals and families together to make life-changing connections with peers, support networks, services, and treatment providers.

Share your tools and resources with patients and families. Get feedback on treatment technology from the world’s top BFRB researchers. Recruit participants for your advocacy work and research studies. Get involved today at bfrb.org/sponsor.

InTouch is a quarterly publication of
The TLC Foundation for Body-Focused Repetitive Behaviors

Articles and letters may be submitted to leslie@bfrb.org

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Text deadline next issue: January 31, 2019

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.
Join the YAAC!

The TLC Young Adult Action Council (TLC-YAAC) is a group of young adults who, under the guidance of the TLC Foundation’s staff, develop ambassador programs and initiatives to raise BFRB awareness amongst young people around the world.

YAAC Projects include:
- BFRB Awareness Week campaign development
- Diversity and Inclusivity Workgroup
- Scientific Literacy Project
- Social media outreach campaigns

YAAC members are dedicated volunteers who honor collaboration and mutual respect. Members are required to attend monthly meetings and the Annual Conference. Applicants should be between 18-27 years old. Learn more about the YAAC and the application process at bfrb.org/yaac.

Become a Support Group Leader

Start a BFRB support group in your community! To get started, visit http://bfrb.org/volunteer-get-involved/support-group for information and helpful tips on how to organize a support group. Contact outreach@bfrb.org to learn more about how TLC and our volunteer Support Group Leader Mentors can help you create a vital resource in your community.

Volunteer Coordinators Needed

A volunteer coordinator plays a vital role by liaising with potential volunteers, identifying their talents, and working with TLC staff to match interested volunteers within areas of need. The Volunteer Coordinator helps ensure volunteers feel satisfied that they are making an important contribution to TLC and the BFRB community. This position requires approximately 5 hours per week.

Write for TLC

Do you love to write? Consider writing for TLC! TLC writers may submit original stories or essays and interview BFRB community members for publication on our website, newsletter, and/or various partner blogs. This is a great opportunity for a self-motivated writer to gain experience and bylines with an international organization.

Distribute Educational Brochures

TLC has publications that cover a wide range of information for many audiences. You can assist in spreading TLC’s work in your community by sending brochures to appropriate organizations and offices in your area, including doctors’ offices, schools, and salons. Be creative. Where would you pick up a brochure? It’s simple: you provide the addresses and postage and we provide the brochures.

Share Your Story

Knowing we are not alone with BFRBs can be the most powerful source of healing. Sharing your experience helps others to find help and fights public ignorance and stigma surrounding BFRBs. TLC has an editing team and strategies for sharing stories in print and video with our community and the media. Contact TLC and let us help you share your story. Submit your story at bfrb.org/shareyourstory.

Visit bfrb.org/volunteer for a complete list of volunteer opportunities and application information.
Sharing knowledge.

Education Programs and Media Outreach

Raising awareness to end stigma and sharing best practices for treating and supporting people with BFRBs

43 licensed mental health clinicians from 15 states + Canada completed TLC’s Professional Training Institute!

33 Volunteer BFRB Ambassadors completed outreach training and began representing TLC at events in 4 regions:
- Mid-Atlantic States
- Northern CA
- New York - New Jersey
- Minneapolis

TLC Ambassadors Hannah Thompson left, and Sarah Pennington (right) with International OCD Foundation Executive Director Jeff Syzmanksy, at the Annual Mental Health Advocacy Walk in Washington DC.

50+ Accurate News Stories on BFRBs
TLC connected experts to journalists that resulted in coverage on:
- Mosaic
- The Atlantic
- NPR
- Health.com
- Self.com
- Insider
- Refinery29

Model and actress Sara Sampaio partnered with Victoria’s Secret to raise $67,000 for TLC. Sara was inspired to help the BFRB community after sharing her own trichotillomania story on Instagram, and plans to continue raising awareness of BFRBs.
Supporting recovery.
Connecting Our Community
Creating life-changing connections that end shame and foster healing

We’re grateful to volunteers like Anita, Tiffany, and Jennifer (from left) who joined Kaprece (right) in leading TLC’s diversity efforts this past year, and we’re looking forward to providing more opportunities to increase the inclusivity of our community.

Building DIVERSITY

4 Ways Your Gifts Support Inclusivity

1. Provided access to the TLC community and educational resources for people of color through direct outreach and scholarship awards.

2. Increased presence of BFRB information at multicultural events by sending staff and volunteers to the Bonner Bros Hair Show, Natural Hair Show, and a Henrietta Lack community event.

3. Helped TLC representatives attend or organize multicultural focus group meetings to increase understanding of mental health resources needs in various cultures. Learn how you can help at bfrb.org/volunteer.

4. Supported YAAC efforts to learn how TLC can better serve underrepresented communities by hosting a Special Interest Group luncheon at the conference and conducting a series of interviews with people from diverse backgrounds. Read the interviews at bfrb.org/diversity.

7% increase in BFRB peer support groups in 2018. A new volunteer-led support group mentorship team provides support to group leaders in order to improve group sustainability.

$10,400 raised by 85 fundraisers who ran peer-to-peer fundraising campaigns on Facebook in 2018. Given the history of shame caused by BFRBs, this is a phenomenal achievement for our community.

711 people attended TLC events and activities

$11,725 event registration scholarships awarded

www.bfrb.org

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Update: BFRB Precision Medicine Initiative Moves Forward

Scientists completed the data collection phase of the groundbreaking BPM study ahead of schedule due to the smooth flow of operations and steady recruitment of volunteers. Researchers were deeply moved by how motivated people were to participate—to be part of something that offers hope for a cure for BFRBs.

The BPM researchers will now get to work writing papers, with the most relevant and important findings of the research disseminated by the end of 2019. Papers include identifying subgroups of people with BFRBs, developmental aspects of how BFRBs manifest in children and adolescents, and genetics. What this means is that we are getting much closer to identifying specific treatments for individuals.

In fact, Darin Dougherty, MD, MSc (TLC Scientific Advisory Board) Director, Neurotherapeutics Division, Massachusetts General Hospital, Harvard Medical School believes “that thanks to our investment in the BPM Initiative, BFRB treatment will be able to catch up to the 70% remission rates of similar disorders within 3-5 years.”

The BPM initiative is now moving into Phase 2, where the focus is on grant writing and outreach to funding agencies. The TLC Foundation will support this by organizing a weekend retreat in early 2019 for the BPM researchers to collaborate on grant writing proposals to submit to funding agencies, including the National Institutes of Health.

ComB Study Update

TLC donors also funded a clinical trial of the Comprehensive Model for Behavioral Treatment (ComB) at American University. Principal Investigator David Haaga, PhD, reports enrollment is going well with 28 of 42 participants enrolled, and 17 of the 28 have completed post-treatment assessment. Although investigators are not analyzing results along the way and therefore not yet reporting on treatment outcomes, they are making headway toward getting the answers we need about this well-known but understudied treatment.

As a result of this study, five therapy trainees (1 post-doctoral from the Behavior Therapy Center of Greater Washington, 1 doctoral student from American University, and 3 doctoral students from the Uniformed Services University of the Health Sciences [USUHS]) have completed training in BFRB treatment and are receiving close supervision of their work from leading expert Ruth Golomb, MEd. The 4 grad students are new to BFRB work. The USUHS students will pursue careers in the military, where few, if any, clinicians are trained in ComB. Thus, independent of the research outcomes, this study is helping to spread interest and expertise in BFRBs to a new generation of treatment providers.
Body-Focused Repetitive Behaviors and the ICD-11

The International Classification of Diseases is produced by the World Health Organization (WHO). The 10th edition of the classification, developed in 1992, is used by member states around the world. It is crucial in clinical practice (e.g., for addressing reimbursement) and in research (e.g., for collating statistics).

The development of ICD-11 has been a multi-year process. From a mental health perspective, there has been much discussion of Chapter 5 of ICD-11, and its relation to the DSM-5. A draft version of ICD-11 has now been released (view at https://icd.who.int/browse11/l-m/en, so that ember countires can start preparing for implementation.

The ICD-11 Working Group for Obsessive-Compulsive and Related Disorders (OCRD) was chaired by SAB member Dan Stein, and included SAB members Jon Grant and Doug Woods. They reviewed the literature, and made recommendations to ICD-11. Dan also headed up one of the field sites in Africa that collected data to inform the ICD-11 revision.

The OCRD Working Group recommends the inclusion the term BRFBs, and to list trichotillomania and skin-picking disorder under this term. The hope is that inclusion of the term BFRB helps educate clinicians about these conditions, emphasize their distinctiveness from other OCRDs, and underscore the several similarities of TTM, SPD, and related conditions.

The full text of ICD-11’s chapter 5 is not yet finalized and available for distribution. However, like DSM-5 it will provide text on essential features, differential diagnosis, and other key considerations. This text will be freely available in multiple languages, and so again should contribute to raising awareness of BFRBs, and to improving optimal diagnosis and care around the world.

TLC Scientific Advisory Board Member Nancy Keuthen, PhD, joined BFRB Ambassador Liz Atkin in Germany for the first German Conference on BFRBs. The event was organized by Ingrid Bäumer, leader of the Cologne Skin Picking Support Group, and TLC 2017 Early Career Award Program winner, Christina Gallinat, PhD. Christina shared, “The conference was simply amazing - we really had the TLC feeling of open hearts, understanding, and positivity.” An estimated 150 people attended sessions on current research, treatment best practices, and support options.
BFRB Outreach Update

Wow, this year has flown by! We made great progress in rolling out our Volunteer BFRB Ambassador Program this year and strengthening the support we offer to our Support Group Leaders. To date, we have twenty-five trained BFRB Ambassadors gearing up to spread awareness and educate in their community. Ten new Support Groups have formed across the US and three new international groups are in development. Thank you to all who give their time to serving and leading our community. Without our amazing volunteers, we would not be able to do the important work of ending the shame and stigma caused by BFRBs.

We owe special thanks to Tammy Wannemacher, Susannah West, and Amy Curcio, who donate significant time strengthening our peer support groups by serving as Support Group Leader Mentors. These three ladies do an amazing job providing guidance and mentorship to me as well as our Support Group Leaders. When you see them or talk to them, please THANK THEM for their hard work and countless hours.

I also would like to thank Claire Cameron and Maddie Lapp, who served as interns for TLC this past year as well as being dedicated members of the Young Adult Action Council (YAAC - formerly TLC Millennial Task Force) for all their hard work leading the YAAC and several outreach initiatives within the community. These two young leaders are inspiring and have so much energy!

We are also grateful for our partners that have been 100% committed to our mission and vision by volunteering their time: Bianca Lyder, Aneela Kumar, and Ellen Crupi.

Again, THANK YOU TO ALL VOLUNTEERS who gave their time in serving our community this year.

Our community has expanded this past year, but we are nowhere near done with this work. We need every one of you to continue raising awareness of TLC and BFRBs in your community. To support this, our trained BFRB Ambassadors will begin training medical, therapeutic, and school professionals in best practices for supporting their clients, patients, and students. In this past year, we have developed several volunteer opportunities, from outreach to fundraising to administrative office support. Learn more about these opportunities at bfrb.org/volunteer.

My TLC Family, this is the last article you will receive from me as your National Outreach Manager. I have accepted a position with another organization, but I will still be a HUGE ADVOCATE for our BFRB community. Thank you for welcoming me with open arms.

Our community has a unique bond through TLC and the shared BFRB experience. I love how each of you embraces all members of our community, welcoming and supporting new members and old. You have made my year with TLC quite fulfilling.

~With Love, Kaprece James, MPA

Caped crusaders banded together to raise awareness of BFRBs during our Superhero Cosplay Fundraiser in Minneapolis this past October. Special thanks to the HabitAware team and our professional training faculty for their support of this event!
The Difference You Make

A grateful dad
A struggling son
Pickers and pullers
One-by-one,

You bring strength and hope and help.
In the journey together
we learn to love ourselves.

Uniting each year and creating bonds,
That help us cope the whole year long.

Every gift provides a lift
For a daughter in need
For a mom in distress
Together we help ourselves
Make progress

Toward a future that all of us dream
Where stigma is gone, where help is specific
Where clinicians are trained
In ways scientific.

Where our journeys have meaning
Where our afflictions are few
Where understanding flows
And we see a way through.

In every way, throughout the year
Your gifts to TLC support
Community members far and near.

Throughout our community,
all year long...
Your generous gifts keep TLC strong.

Please keep our momentum
going into 2019!

Visit bfrb.org/donate to make a gift
today.

Love from all of us at TLC

Poem by Corinne Lightweaver, TLC Annual Fund Director
Dear friends,

I hope you are feeling full of pride as you read this newsletter. Together, we’ve accomplished a lot this year! Thank you to all of you who volunteer, participate in research, speak out in your communities, post online, fundraise, attend support groups, or devoted your careers to advancing the treatment of BFRBs. You truly are superheroes!

I’m very excited about the progress that 2019 will bring with your support. As you think about your year-end giving, let’s take a peek at some of the programs your gift will play a vital role in making possible:

**BFRB Educator Trainings** – Our trained Volunteer Ambassadors will launch trainings in our pilot regions this coming year, educating school personnel, medical and therapeutic professionals, and cosmetologists on best practices for supporting students, patients, and clients with BFRBs.

**Young Adult Action Council** – The council provides opportunities for deeper involvement and the growth of the next generation of BFRB leadership and develops outreach programs targeting youth in our community.

**BFRB Awareness Week** – October 1-7, we fight the shame and stigma of BFRBs and reach hundreds of thousands of people with education and resources.

**Scholarship Fund** – This fund provides access to life-changing experiences for individuals in need who wish to attend TLC events and conferences.

**Early Career Award Program** – This program fosters interest in the field of BFRBs by the next generation of BFRB clinicians and researchers, connecting them to mentors in the field.

**Spanish Language Resources for BFRBs** – 2019 will see the launch of a new Spanish-language version of bfrb.org. A team of volunteers has translated important sections of our existing website, the first step in the development of support and educational resources for the Spanish-speaking members of our community.

**Treatment Research** – Your donations will fund the final year of a randomized controlled trial of the Comprehensive Behavioral Method of Treatment, (ComB), underway at American University.

**BFRB Precision Medicine Initiative** – In the coming year, we will complete the current phase of the Initiative. Our investigators will be hard at work analyzing the unprecedented amount of data collected from more than 300 participants, launching the genetics arm of the study, and, most excitingly, sharing with you what they’ve learned and the implications for new and improved treatment approaches.

These important projects only scratch the surface of what your gifts to TLC accomplish.
You make it possible for TLC, our Scientific Advisory Board, and our volunteer Ambassadors to provide accurate, evidence-based information about BFRBs to our families, the media, our schools, our pediatricians, our therapists, our salons and cosmetologists. **Without TLC, where would we go for trusted information?**

You provide our community with referrals to knowledgeable BFRB therapists, support groups, salons, and services. You enable us to answer the phone calls and the emails from people feeling desperate and alone. You provide the advice and mentoring to help volunteers start and maintain new support groups. **You provide healing.**

**You move our field forward.** Your support enables TLC and our Scientific Advisory Board to advocate for important changes in the scientific field – like the addition of Skin Picking to the DSM-5 in 2013, and the recent update of the ICD to include “Body-Focused Repetitive Behaviors” as a category of disorders. **Who made that happen? You did,** by bringing together the top clinicians and researchers in this field to serve on our Scientific Advisory Board and develop the strategic direction for BFRB research.

**You put us to work.** There is no other organization in the world doing what TLC does for our BFRB community. All of us on TLC’s staff are grateful and honored to devote ourselves to this cause, day in and day out. Many of us on the staff have BFRBs personally or in our families. Others of us have grown to love this community because you are just plain lovable! All of us care tremendously about this cause – and about you. **Please give yourself a hug of thanks from us – and please remember to donate to keep us as busy as possible in 2019.**

Thank you!

With love and gratitude,

Jennifer

P.S. **Kaprece James has found a new position working to support military families like her own. We will miss having her on staff, but you all did a wonderful job of charming her and hooking her into our cause. She plans to remain an active part of our community and hopes to see you at the Conference in May! We remain committed to the work she started for us as our first National Outreach Manager and building diversity within our community. Best wishes, Kaprece!**

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**Have you heard of TLC?**

We love the world of artist Shan Cholakian where everyone has heard of TLC. Shan has picked her skin as long as she can remember. She’s made autobiographical comics for four years now, but only recently changed the focus of her comics to be about her BFRB. She currently lives in Seattle, WA and is about to celebrate her first year of treatment anniversary. You can find more of Shan’s comics on Instagram under the handle [@spraynwash](https://www.instagram.com/spraynwash).
Get Involved

Order Awareness Kits for Local Outreach

Order our pre-packaged Awareness Outreach Kits to distribute to therapists, dermatologists, and cosmetologists in your area. Each kit includes 10 brochures about BFRBs, including hair pulling disorder and skin picking disorder information, 10 cover letters, and 10 TLC envelopes. All you have to do is address the envelopes, add postage, and send them off! Get your kits at store.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!

NEW SUPPORT GROUPS

You are not alone! Get details on these and other groups in the US and 8 other countries at www.bfrb.org/support

SAN FRANCISCO, CA
New location! Group meets every other Thursday. Sign up for group emails and notifications by contacting SFbfrbTWB@gmail.com

SANTA BARBARA, CA
A free peer support group for young adults (17-29) who have a BFRB. Send an email to SBbfrbgroup@gmail.com to RSVP, receive the location information and with any questions.

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.

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