A TLC Research Initiative
CREATING NEW HOPE
and New Treatments
for Hair Pulling and Skin Picking Disorders
RE: WE NEED A NEW APPROACH TO BFRB RESEARCH

Dear friends,

The best research suggests that 3% or more of the population lives with hair pulling or skin picking disorders, also known as BFRBs (Body-Focused Repetitive Behaviors). That’s more than 10 million people in North America alone. Today, there are very few treatment options available for them, and typical success rates are only 10-20%.

Drastic cuts in federal funding make it nearly impossible to secure public money for BFRB research, leading to chronically underfunded research efforts that have failed to produce new treatment options. As a result, we still lack foundational scientific knowledge about the genetic and biological mechanisms for hair pulling and skin picking disorders.

With your help, we have an opportunity to transform the entire landscape of treatment possibilities for hair pulling and skin picking.

Let us share with you TLC’s vision for the BFRB Precision Medicine Initiative.

Sincerely,

Jon E. Grant
Don’t you think it’s **time we created better solutions** for ourselves and our children?

“I’ve been pulling my hair out for over 30 years.”

“My doctor had never heard of trichotillomania.”

“My parents took me to doctors, therapists and treatment programs all over the state.”

“We’ve spent thousands on counseling and the behavior always returns.”

“I’m tired of suffering.”

“I have tried absolutely everything.”

Supporters and sufferers gather for a group photo at a recent TLC event.
Two, unique girls...

BANDAGES WON'T CURE MY DAUGHTER'S SKIN PICKING

My daughter Molly started picking her skin when she was five years old. By first grade, she'd have forty to fifty open sores on her body at a time. People would stare and ask her if she had chicken pox or poison ivy. Her clothes were always covered with blood.

For years, I tried to prevent her from picking any way I could. At night I'd put socks over her hands, securing them in place with tape. Each morning I'd clean her wounds, cover them with bandages, and then place tubular gauze over her arms and legs, taping the openings to her skin. I tried rewarding her with money for making it through a day without picking. I purchased bandages online by the case.

Molly started seeing psychiatrists and therapists at age six. I've taken her all over the country and spent thousands of dollars seeking an effective treatment. At a special clinic in Hartford we were told, "We can treat her if you want, but there's almost a 100 percent relapse rate." We left feeling discouraged and defeated. We've tried various medications and supplements including Prozac, Inositol, and NAC. None of these treatments has been able to cure her skin picking.

Molly now has permanent scarring on her face and back. She's had two bouts of cellulitis, a dangerous skin infection. Today, as a young woman in college, she has had to learn to cope with and manage this disorder on her own. I'm proud of how well she has done, but I know she struggles daily.

As a mother, I just want her to be able to live her life--to take a shower or look in the mirror or wear a short-sleeve shirt without fear that she'll pick her skin, to have friendships and dreams and adventures without having to spend hours a day managing her skin. If I could have one wish in the world, it would be to see my daughter free of this disorder once and for all.

Molly's Story

Lily and her mother.
Two, unique girls... the SAME STORY.

COMMON ISSUES FOR MILLIONS OF PEOPLE WITH BFRBs

- THEIR BEHAVIOR BEGINS WHEN YOUNG
- THEY ENDURE YEARS OF SUFFERING
- THEY EXHAUST ALL TREATMENT POSSIBILITIES and are forced to manage their lives around daily picking and pulling

You can help change their story.

We have an opportunity, through the BPM Initiative, to make sure that Molly, Lily, and millions like them have effective treatment options just a few short years from now.

... the SAME STORY.

I DON’T WANT TO WEAR A WIG FOREVER

It was my first home game on the basketball team. There were 400 people in the bleachers and I was crying in the locker room because I was so terrified to go out in front of the whole school without my wig on. I did manage to finish the season, but every single game my heart was still pounding like crazy when I left the locker room.

I started pulling out my hair in second grade. By seventh grade, I was completely bald and had to start wearing a wig. I still spend one or two hours every day pulling. My mom says that my grandfather used to pull his hair too, so she’s worried about trichotillomania getting passed on in our family.

I’ve tried everything possible to stop pulling, but nothing seems to help: medications, supplements, therapists, acupuncture, reiki, and every fiddle tool there is. Every time I try a new medicine or treatment, I secretly get super-excited and think, “Maybe this will be the ONE and I won’t have to pull anymore.” Then I’m more discouraged than ever when it doesn’t help. I’ve pretty much given up on medicines now, because it’s so disappointing to try another one, get my hopes up, and then have it not work again.

I’m really nervous about starting high school this Fall—being at a new school, where I won’t know anyone, and getting all the questions and looks from other kids. I’ll be playing varsity soccer, so everyone will see me without my wig. It’s exhausting having to explain trich over and over, and knowing that people still won’t understand.

I would give anything to be able to stop pulling. I just want to live a normal life—playing soccer, going swimming, having slumber parties—without being constantly embarrassed and self-conscious about my hair. The best birthday present ever would be something to help me stop pulling once and for all.

I DON’T WANT TO WEAR A WIG FOREVER

It was my first home game on the basketball team. There were 400 people in the bleachers and I was crying in the locker room because I was so terrified to go out in front of the whole school without my wig on. I did manage to finish the season, but every single game my heart was still pounding like crazy when I left the locker room.

I started pulling out my hair in second grade. By seventh grade, I was completely bald and had to start wearing a wig. I still spend one or two hours every day pulling. My mom says that my grandfather used to pull his hair too, so she’s worried about trichotillomania getting passed on in our family.

I’ve tried everything possible to stop pulling, but nothing seems to help: medications, supplements, therapists, acupuncture, reiki, and every fiddle tool there is. Every time I try a new medicine or treatment, I secretly get super-excited and think, “Maybe this will be the ONE and I won’t have to pull anymore.” Then I’m more discouraged than ever when it doesn’t help. I’ve pretty much given up on medicines now, because it’s so disappointing to try another one, get my hopes up, and then have it not work again.

I’m really nervous about starting high school this Fall—being at a new school, where I won’t know anyone, and getting all the questions and looks from other kids. I’ll be playing varsity soccer, so everyone will see me without my wig. It’s exhausting having to explain trich over and over, and knowing that people still won’t understand.

I would give anything to be able to stop pulling. I just want to live a normal life—playing soccer, going swimming, having slumber parties—without being constantly embarrassed and self-conscious about my hair. The best birthday present ever would be something to help me stop pulling once and for all.
This is an extraordinary opportunity to change the course of the future for ourselves, our families, and the next generation growing up with BFRBs.

**IMAGINE IF**...

- We could pinpoint each person’s BFRB profile, identifying the motivations and habits that make up an individual’s particular type of picking or pulling behavior.
- We could match that BFRB profile to specific genetic and biological origins.
- We had a suite of treatments carefully tailored to these genetic and biological factors for each BFRB profile.
- Those treatments resulted in complete BFRB remission for 7 out of 10 people.
Precision Medicine Will Make It Possible

WHAT IS PRECISION MEDICINE?

Precision Medicine is the cutting edge of medical research and treatment. Across the medical spectrum, we are learning that complex diseases and disorders require very individualized therapies. The BFRB Precision Medicine Initiative is bringing these proven research strategies to bear on BFRBs.

Precision Medicine uses genetic and biological indicators to describe an individual pattern of disease. It has revolutionized cancer treatment, and the National Institute of Mental Health has identified Precision Medicine as the key to discovering transformative new treatments for mental health disorders.

Precision Medicine begins with the understanding that external symptoms are not the best guide to selecting treatments. Two individuals with tumors in their lungs might require very different therapies, based on the genetic characteristics of those tumors. Likewise, we know that two people who pull out their hair or who pick their skin respond differently to the same treatments, underscoring the importance of unique patient approaches based on the genetic and biological sources for their behaviors.

The BFRB Precision Medicine Initiative is founded on a belief that this cutting-edge approach to research and treatment will transform the landscape of treatment possibilities for hair pulling and skin picking.

“Precision medicine for mental disorders could be even more transformative than for cancer.”

— Tom Insel, M.D., Director of National Institute of Mental Health

Felicia’s genetic and biological indicators are vastly different from her friend’s. Just as no two snowflakes are alike, the diversity of indicators is immense and they are key to successful treatment.
The BPM Initiative is driven by unprecedented collaboration among the leading BFRB researchers. Precision Medicine has emerged as the gold standard for medical research and will enable us to rapidly identify new BFRB treatments.

For the first time ever, the investment of private donors will provide BFRB research efforts with adequate funding.

Ongoing dialogue with the National Institute of Mental Health and the pharmaceutical industry position the BPM Initiative for future collaboration and partnerships.

By the end of Phase 1, we expect to identify three to six different BFRB patterns of symptoms or profiles. These profiles will point us to different promising treatments for given individuals (precision medicine). This research initiative will point us to the most effective points of intervention for new treatments and promising research.

**BFRB DATA BANK**
BPM scientists will compile and integrate patient data from past smaller studies into a single BFRB patient database and made available to all researchers.

**PILOT STUDY**
Test and refine behavioral protocol and genetic and neurological assessments for first 66 participants at UCLA, University of Chicago and Massachusetts General Hospital.

**FULL IMPLEMENTATION**
Conduct full BPM assessment protocol with approximately 150 additional participants across the three University sites.

**REMAINING ASSESSMENT**
Conduct full BPM assessment protocol with approximately 80 remaining participants across the three University sites.

**PHASE 1**
Years 1-3

**CURRENT RATE OF BFRB TREATMENT SUCCESS**
10-20%
Poised for Rapid Success:

**COLLABORATION** The BPM Initiative is driven by unprecedented collaboration among the leading BFRB researchers.

**SCIENCE** Precision Medicine has emerged as the gold standard for medical research and will enable us to rapidly identify new BFRB treatments.

**FUNDING** For the first time ever, the investment of private donors will provide BFRB research efforts with adequate funding.

**ENGAGEMENT** Ongoing dialogue with the National Institute of Mental Health and the pharmaceutical industry position the BPM Initiative for future collaboration and partnerships.

**NEW TREATMENTS**
The genetic and biological patterns that we identify in Phase 1 will allow us to identify promising new treatments.

**CLINICAL TRIALS**
With additional public and private investment, the BPM Initiative will conduct clinical trials of new BFRB treatments.

**7 Years | 70% Treatment Success**
With your support, we are confident the BPM Initiative will achieve successful BFRB treatment rates of 70 percent or higher within seven years. This is an ambitious goal. **We owe it to the millions who live with these disorders to set our sights high.**

Medical research has already achieved similar treatment success rates in other, more complex mental health disorders such as depression and schizophrenia. The National Institute of Mental Health has identified Precision Medicine as the approach that will produce the most rapid breakthroughs in mental health research.

**PHASE 2**
**YEARS 4-7**

**Identify new treatments tailored to each person’s BFRB profile.**
THE NEED FOR NEW TREATMENT OPTIONS IS URGENT. Hair pulling and skin picking disorders affect millions of people; and yet their likelihood of long-term remission, based on today’s treatments, is extremely low.

We have consensus across the entire research community around this approach. There is no other BFRB research effort of this scale or with this degree of support anywhere in the world.

Together, with your support, we can make an incredible difference—we can change the landscape of BFRB treatment possibilities forever.
Meet the Boswells
My 17-year-old daughter, Taylor, recently started pulling her hair. As her dad, it breaks my heart to see her suffer. So, I spent seven months learning everything I could about trichotillomania. I was shocked to learn that there are very few, if any, effective treatment options. We tried all kinds of prescription medicines. We tried dietary supplements. We met with therapists and psychiatrists. And still, we struggle to find the answers that will help our daughter.

Our family is supporting the BPM Initiative with one of the largest philanthropic gifts we have ever made. We intend to do everything in our power to ensure that this suffering ends, for Taylor and for the millions of people like her, who live with BFRBs every day.

We hope you’ll join us.
We Are the Ones

If...

you live with the daily challenge of hair pulling or skin picking,
you have visited countless therapists, doctors, and workshops, and find the consistent lack of answers maddening,
you want to spare others the suffering that you and your family experience,

then

you understand the critical need for this research. Please join with us and support TLC’s BPM Initiative to help provide a brighter future for those who suffer hair pulling and skin picking disorders. SUCCESS WILL DEPEND ON ALL OF US.

For more information or to make a donation towards the BPM Initiative, please contact TLC Executive Director Jennifer Raikes at jennifer@bfrb.org or 831-457-1004.