News and Updates on TLC’s BFRB Precision Medicine (BPM) Initiative

Launch Time! BPM Initiative Moves from Planning to Implementation

After more than 18 months of rigorous planning and design, the BPM Initiative is ready to launch its first research activities.

QUICK TAKES:

1. Rising to the “challenge”: BPM Initiative reaches $1M milestone

2. The Haslams, a family touched by BFRBs, make visionary challenge gift

3. 800+ patients’ data to be combined in largest ever BFRB database

4. BPM pilot study takes off

Great News! Sixteen months after the public launch of our BPM Initiative, we have reached the $1M fundraising milestone. This is a historic moment both for TLC and for everyone affected by BFRBs.

What will this $1M mean for the BPM Initiative? It means that our Stage 1 research efforts are now fully funded – we’ll be able to hire the BPM Director, compile and analyze our 800-patient database of past BFRB data, create the databases for the new clinical, biological, genetic and neuro-imaging data to be collected, and, most importantly, we will be able to complete the pilot study that tests our research protocols and sets the stage for scaling up our research.

To each and every person who has already supported the BPM Initiative, I want to say thank you on behalf of the whole TLC community. You are helping to create a new future for all of us. I hope you take great pride in what your gifts are accomplishing!

We will be shifting next to fundraising for Stage 2, supporting the full launch of BPM research efforts.
Brian Haslam is Founder and CEO of Cityworks, a Utah-based software company that helps cities and public utilities manage their infrastructure. Brian and his wife Michelle recently pledged a $200,000 challenge gift towards the first stage of BPM research activities. Over the summer, their gift inspired more than a dozen other donors to make new contributions towards this matching goal. Brian is also a TLC Board member and Chair of the BPM Initiative’s fundraising campaign. Below, Brian relates a turning point in his own dedication and support for the BPM Initiative:

A few months ago, I hosted a gathering for some of our BPM scientists at my company’s offices. One afternoon, I was standing at the airport with Dr. Jon Grant, our Scientific Advisory Board (SAB) Chair, talking about the amazing sacrifice of our SAB members and how their research has provided so much hope for those who desperately seek help, including for me and my family. Jon shared how these scientists have been so dedicated to BPM that many of them have already kick-started the research through their own self-funded efforts. Then Jon then said to me, “You know Brian, if we don’t succeed in raising some serious funding for TLC’s BPM research initiative, I’m afraid that between the disappointment of our scientists, and the pressures from their institutions to bring in funded research, it could mean the end of research for BFRBs.”

That just hit me like a truck.

Our family has spent many years trying to support my daughter Katie in her journey with hair pulling. About 10 years ago, when Katie was 17, we reached our rope’s end. We had tried everything – medications, therapists, doctors, supplements – but Katie was just kind of collapsing. Her hair pulling was getting worse, her anxiety was off the charts, and her depression was terrible. We saw therapists who were baffled by Katie’s combination of symptoms. We had countless appointments with doctors who had never heard of Trichotillomania and just wanted to prescribe heavy medications for depression and anxiety. We suffered through years of mis-diagnosis and ignorance, which all had a very tragic impact on our daughter’s life.

I don’t want other families to have to go through what we did. So when I heard Dr. Grant say that failing to raise significant funding for BPM could mean the end of BFRB research, I knew that this was a critical time and I needed to find a way to do something.

I talked it over with my wife Michelle, and we decided after considerable discussion to pursue opportunities for restructuring my company Cityworks in order to free up substantial resources in support of the BPM Initiative. Most of our assets are tied up in the company that I’ve been building for the past 30 years, so although it wasn’t a step we had been expecting to take, we both felt it was the right thing to do at a very important moment for our BFRB community.

Together we decided to make a $200,000 challenge gift, hoping to inspire others to join us.

As families and individuals affected by BFRBs, I want people to know that we have an incredible opportunity right now. Our actions today will create a different future for every generation of BFRB-sufferers to come. But it depends entirely on us to ensure that this effort is adequately funded. Michelle and I hope you’ll join us in supporting the BPM Initiative’s groundbreaking work.

Because the BPM Initiative has been designed from the beginning as a collaboration among multiple researchers, we now have the opportunity to combine patient data from past research efforts of several different BPM scientists. The result will be a total of more than 800 patients’ data, integrated into the largest-ever database of BFRB patient data. This data will provide the foundation for helping to identify more effective, individualized treatment protocols for hair pulling and skin picking disorders. Drs. Jon Grant (University of Chicago), Nancy Keuthen (Harvard University), and Christopher Flessner (Kent State University) are already actively working on this project. We expect to have two more scientists join them in the coming months.

This database will be the foundation for all TLC’s future research, allowing us to compare findings across a larger sample size than any previous BFRB research efforts.
The BPM Initiative will accept its first 30 study participants in early 2016, launching the first full application of precision medicine in a BFRB-focused research initiative. It is the power of precision medicine - combining brain scans, blood markers and behavioral assessments - that will provide the key to unlocking new treatment possibilities for everyone who lives with hair pulling, skin picking or other BFRBs.

TLC is currently working with each of the three pilot study research sites – UCLA, University of Chicago, and Harvard University – to establish all the necessary agreements and approvals to proceed with these first 30 patients. As with any research effort involving human subjects, the approval process can be complex and time consuming. Each institution has an internal review board process, which can take multiple months in some institutions. The role of the BPM Director will include overseeing this approval process to ensure it runs as quickly and smoothly as possible.

The pilot study will provide us with hands-on experience implementing the BPM study design, and an important opportunity to “work out the bugs,” prior to full study implementation. As an example, it may take up to a full day for BPM study participants to complete the necessary behavioral assessment, blood draws and brain scans. Through the pilot study, we may find that this process is too exhausting for participants, which would compromise the validity of the data collected, requiring us to administer assessments over 2 or more days.

With this pilot study, all of our staff and scientists’ planning efforts over the past two years are finally moving into the implementation stage – a very exciting turning point for the whole BPM Initiative!

**RECENT BFRB NEWS:**

You might appreciate this recent media and internet coverage related to BFRBs and the BFRB Precision Medicine Initiative:

**Blog posting by NIMH Director Dr. Tom Insel**, about why precision medicine is the leading edge for mental health research (February 2015):

http://www.nimh.nih.gov/about/director/2015/precision-medicine-for-mental-disorders.shtml

**Article by TLC community member Katie Koppel** in xoJane, about living with trichotillomania:

http://www.xojane.com/it-happened-to-me/living-with-trichotillomania

Katie’s article is a great example of a courageous woman’s journey in managing her hair pulling, despite the lack of successful treatment options for her. It’s a great example of why the BPM Initiative is so historic and important – we owe it to millions like Katie to find better treatment solutions that will offer them a very different future.

If you have additional questions about the BPM Initiative, please contact TLC Executive Director, Jennifer Raikes, at jennifer@trich.org or (831) 457-1004.
TLC has been the trusted leader in BFRB education, advocacy, and research for over twenty years. The groundbreaking BPM Initiative is an exciting turning point in our history—a bold step towards a brighter future for all of us.

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

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