Guidelines for Starting & Maintaining a Peer Support Group

For more information please visit: www.bfrb.org
**DISCLAIMER:**

Please keep in mind these guidelines are suggestions from The TLC Foundation for Body-focused repetitive behaviors based on years of experience assisting peer support groups to grow and thrive. The TLC Foundation cannot be responsible for the management of peer support groups, but we will work with you as a team to promote your group and will share information to assist you in the organizing process. Peer support groups are intended to provide motivation, education and a supportive community. They are not intended as therapy or treatment for BFRBs or any mental health disorder. As a reminder TLC and peer support group leaders are not able to provide medical or psychotherapeutic advice or treatment.

Resources adapted from 2013:

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- **Jennifer Raikes** - Executive Director, The TLC Foundation for Body-Focused Repetitive Behaviors

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Message from The TLC Foundation for BFRBs Executive Director

Dear Friend,

For many of us coping with Body-Focused Repetitive Behaviors (BFRBs), they are a deeply isolating experience. Finding community with other people going through similar struggles is healing in many ways. I credit my own participation in a weekly peer support group with a big role in my recovery, and the maintenance of that recovery, from trichotillomania.

The experience of sharing a laugh or a cry with people who really understand was invaluable to me. Getting to know the other wonderful people living with BFRBs made me more sympathetic to my own struggle – less self-critical. And yet the accountability that came with those weekly check-ins to my peers also made me more self-aware (or mindful) of my BFRB behavior, and more motivated to make changes. I learned hundreds of tools and techniques to help resist or prevent my urges. I grew to love the other members of my group – and I cherish many friendships that still endure, twenty years later.

We hope this document helps you get started as a peer support group leader. TLC & offer many additional programs to support you throughout the experience. It can certainly be challenging at times to lead a group – but having done it myself weekly for a decade, I can tell you it was well worth the effort.

I encourage you to give it a try!

With love,

Jennifer Raikes,

Executive Director

The TLC Foundation for Body-Focused Repetitive Behaviors
How to START a BFRB Support Group

Starting a successful support group for BFRBs takes passion, commitment and dedication. At first it may seem like you are not reaching out to all the people you can, but in time your group will grow! Not every meeting will have large numbers of members attending, but it is still important to remember why you wanted to start the support group in the first place.

Living with a BFRB can be lonely, confusing and frustrating. Having a support group to go to is an outlet for anyone who has questions, needs support, and wants to learn different ways to cope, or just wants to meet other people who have BFRBs. By organizing these meetings, you will help not only yourself, but also dozens of people just like you who haven’t had anywhere to turn. The TLC Foundation for BFRBs is here to support you at every stage of running a support group - just reach out and we will be there!

The 7 Basic Steps

If you have any questions or concerns at any step contact TLC at TLCGroupLeaders@bfrb.org or call 831-457-1004.

Step 1: Assess Your Readiness

- What are your expectations for the support group?
- How do you hope to benefit?
- How will it affect you if the group does not meet your expectations?
- Are you likely to move soon?
- Are you coping with high levels of stress at the moment?
- How much time do you have to devote to it?

A successful support group requires holding consistent meetings, especially at the start. You should be ready to commit to hosting the group on a regular basis – whether weekly, biweekly or monthly - for at least six months until the group takes hold and you find additional participants to share responsibility.
Step 2: Choose a Format for the Group

There are infinite possibilities for how to structure your meetings, and you will likely adjust the format as the group develops. But before you can invite others to join the group, you need to make a few basic decisions.

As with picking the time or location, you need to make choices that work for you. If these choices don’t meet your own needs, then you will lose motivation to continue leading it – which won’t be good for anyone!

Here are some of the things you will want to take into consideration when deciding the group’s format:

Who is the group for?

- Ages of the attendees – adult only, parent only, children only, mixed age?
- Is the group open only to individuals with BFRBs – or can friends/family attend?
- Can new members begin attending at any time?

Any of these choices can work well, but should be carefully considered. In general, we suggest separate groups for kids and adults, as appropriate discussion topics can be quite different. The HEART support group for kids/teens in Long Beach, CA, holds a separate simultaneous meeting for the parents, who often need just as much peer support as their children!

Most groups welcome new members to begin attending at any meeting. But some successful groups have chosen a “closed” format, which enables a small group of people to meet together regularly without the dynamic of getting to know new people each week. They then hold periodic “open” meetings, which new people can attend.

What is the meeting format of the group?

- **Peer-led versus Therapist-led** - If you choose to work with a therapist, the group may take the form of group therapy, which is a different goal than peer support, and may involve a fee --- the advice in this document is geared to a peer-group format.
- **12 Steps** - The 12 Step format can work well and is worth reading more about, as it will likely be brought up by group members. Most BFRB groups are not 12-Step in structure, but are structured around attendees checking in, followed by a group discussion.

See “Additional Readings” at the end of this document for supplemental reading and resources for group formats.

Step 3: Create an email contact for the Support Group

We recommend using the name of your town/city followed by BFRB, or vice versa (Example: BFRBSantaCruz@gmail.com or SantaCruzBFRB@gmail.com). Once you have this email setup it will be your main tool to communicate with the public. Set up an appropriate signature for the account. We suggest something similar to:
Your Initials or Name,

**BFRB Santa Cruz Support Group**

*For more info on BFRB’s please visit or [www.bfrb.org](http://www.bfrb.org)*

In addition to your email account, you can create a few social media outlets such as Facebook, Twitter, Instagram, or Tumbler dedicated to sharing news about the support group and for posting upcoming dates, interesting reading materials, news from TLC etc. We suggest sticking to the naming structure “BFRB your city”, or “your city BFRB SUPPORT” for social media outlets.

**Step 4: Choose a day of the week/time that works for YOU**

As the leader you will need to be able to attend most meetings. We suggest doing weekly, every other week, or once a month depending on your availability. For example: The Toronto group has meetings every other Tuesday at 7:30-9:30PM, and because of the increase in members it offers a Sunday meeting from 1:30-3:30PM only once a month. It is most effective if there is a regular time/place for the meetings – and that it is held consistently without cancellations.

You also need to choose how long the meetings will be (though of course, as the group evolves, this decision may change.) The best meeting length will depend, in part, on how frequently the group is meeting and how far people have to travel to attend. In general, we find an hour and a half to be a good meeting length.

**Step 5: Find a location**

Start by reaching out to your local community center, library, churches, school contacts, etc. to seek a FREE meeting space. To assist you in this process, we’ve drafted a letter called “Location Letter Template,” which can be found in the additional resources section. You will want to ensure you emphasize the meetings are a **no-fee, PEER SUPPORT GROUP**. Suggestions of places to send your letter to: contact a local government representative to ask if they can assist you. Perhaps you have a personal connection with someone who runs a business/has a boardroom you can use! Use your imagination and you will find a location in no time.

*NOTE: For your safety, we do not suggest running a support group from your home.*

**Step 6: Set a date**

Once you have a location, make sure to pick a date for your first meeting! Give yourself at least a month’s lead-time to spread the word effectively – and for TLC to help you promote the group.
Step 7: Promote your Group - Ask TLC to help!

Provide TLC with a description of your group and its contact information, we can then begin promoting your support group on various Social Media Outlets including our websites. We can also send you educational pamphlets/posters to hand out at meetings.

Spread the word via social media (Twitter, Facebook, Instagram, and TLC’s website), local news outlets, community calendars, emailing local mental health groups, hospitals, etc. The more you communicate about this group, the more likely it will be successful!

CONGRATS!

It is time to host your first meeting! You will be helping many people in your community, who will truly appreciate your hard work and dedication for getting this support group up and running.
How to RUN a Support Group

So you’ve completed steps 1 through 7 in “How to START a Support Group”, now what?

It’s time to think about how you would like to RUN your support group. As a support group leader, you are not expected to be a BFRB therapist or even an expert. You are bringing people together, and helping to facilitate effective interaction among the group. It’s important to remember that these support groups are PEER run. You are the leader, but it will be a group effort to have these meetings become successful. Be original and share ideas with other TLC peer support leaders so they can provide support and share tips with you. Get creative, have fun and learn from one another.


Getting the Conversation Started

What to do for your first meeting and how to keep the conversation going:

Opening Statement

Begin each meeting with an opening statement, like the one created by TLC’s founder Christina Pearson (located in the Addit’l Resources Section) can help to set the tone and expectations for the meeting. It provides some ground rules to refer back to, if discussion strays into unproductive areas.

Roundtable Highs & Lows

The New York group starts each meeting by going around in a circle and asking each member a “HIGH/LOW” of their week. A HIGH can be something positive in their life. A LOW can be something not so great in their life. Highs and Lows don’t have to be associated with hairpulling/skin picking. Keep each one short and under one minute.

Think of Discussion Topics Beforehand

For the first few meetings, we suggest that the group leader prepares topics to discuss relating to BFRBs, such as:

- How having a BFRB affects self-esteem, relationships, school, careers…
- What products can you recommend for hair/skin…
- What have you tried in terms of tips/tricks on trying to stop…
- Ways to deal with stress…
- Have you told friends/family about your disorder…
- Have you tried a specific therapy for your BFRB…
BFRB-relevant Documentaries & Videos

The Toronto group also plays short documentaries on hair pulling, skin picking and other related disorders via YouTube. They use a laptop and usually play one or two videos per meeting. *Each video or documentary usually lasts less than 20 minutes.*

Current BFRB or TLC news

Discuss news relating to BFRBs, important news in the BFRB community – events, webinars, research, etc.

You will find that once you get into the swing of things, you won’t be able to stop talking! There is always something new someone brings to the discussion that keeps the conversation going. Before you know it, the meeting is over! As a group leader, it is important to have a list of topics you may want to use as a way to get conversations started, but most of the time you will find the meeting runs itself. As a group leader it is important to just be aware of the time. Often you will find your group can continue for much longer than a few hours and often becomes a social gathering, which is GREAT! But it may be best to end the meeting on time, so that those who need to get home feel free to leave, while offering the option of continued discussion or socializing afterwards.

Passing the Torch

Once you become an established group and have been running meetings for some time, you can pass the torch and perhaps give individuals the chance to “run a meeting” by having them prepare certain topics or activities that would be of benefit to the group. It is important to understand that as a group leader, you are not there to teach, educate or diagnose anyone. You are there to help make sure things run smoothly and start/end in a certain manner. Remember, it is a PEER SUPPORT group and you are all there for one reason, to find support for dealing with your BFRB.

Other Ideas

If you need to shake things up, why not have your group plan activities to help with the ultimate goal of creating BFRB awareness and educating others? Perhaps you want to plan a fundraising event in your community –e.g. a potluck party, or BFRB Film Screening - with donations going to The TLC Foundation for BFRBs. We suggest you leave a jar near the entrance and leave it up to individuals if they want to give a very small donation of $1-2 at every meeting. It’s not mandatory, but it can help TLC provide you with resources such as posters, pamphlets, etc.

Keeping Organized & Getting Feedback

Another important task of running a support group is keeping a list of your members/communicating with them! TLC will contact you with any potential members who contact us looking for help. Save them in your email list! Here are some ideas:

- Create a word/excel document and list names, and emails (Usually you can do this by having a “sign in sheet” for each new member who attends)
• **Email reminders** to your group members a few days before each meeting

Don't be afraid to have fun, meet new people, and create friendships! If you need help or have questions, you can always email TLC for support.
Questions & Common Scenarios

Here are some questions you might get from people looking to join the support group, or situations you may encounter when you run the group:

Is there any transportation to the meeting?

This is not the Group Leader’s responsibility. You will find in time that most people will offer to give rides and should arrange this on their own.

I’m a parent/friend of someone with a BFRB: can I come to the meeting?

As discussed above, this is an important question to consider when deciding the format of your group. If you would prefer to limit the group to those directly experiencing BFRBs, perhaps, you can have bi-monthly meetings where friends and family members are invited to sit in to ask questions, listen, or learn. If an exception to the normal format is requested by a member, it is recommended that you ask your group members how they feel about it or for ideas of how best to respond.

I am interested in attending, but have no way of getting there, help?

Once again, for safety purposes we do not advise that you initially offer rides to strangers.

Can I have your personal number?

This is up to you.

Someone is a talker.

We all know through school, work, meetings, and other situations, there is always someone who just talks TOO much. As the group leader, it is important to take control of the meeting by reminding people of the time, or redirecting the conversation back to the group. If you have trouble doing this, just say, “Sorry to interrupt – we have to watch the time.”

Someone ISN’T a talker

It takes a lot of courage to come out to a support meeting. Just showing up and listening is a HUGE step. Just don’t make the person feel uncomfortable by pointing out the fact they are not participating. Every once in a while, politely ask them if they would like to add their opinion.
Someone who knows *EVERYTHING*

This is a PEER SUPPORT group run by a group of like-minded individuals coming together for one reason. Unless they are a licensed medical professional with legitimate credentials, they should not be giving medical advice or diagnosing anyone. It is important that people realize support groups are not for giving or getting medical advice.

Someone is coming who doesn’t seem to have an actual BFRB.

The problem with support groups is that sometimes people show up because they may be lonely, think they have a BFRB when they don’t or are not really there for the right reasons. It is important to clarify that each group is for people who have a BFRB.

**Things to Keep in Mind**

It is important to keep in mind that it is human nature to judge people based on their appearance. Sometimes you may have a member who is a hair puller, but they have what seems like perfect hair. Or a skin picker, but you don’t see any “flaws” on their body. Many of us are also masters of disguise!

It is important to remember, they may have stopped currently, and they have the same feelings on the inside and share the same experiences you or I have had. Some of us want to stop, some of us are content living with these disorders, and some have already stopped, this doesn’t mean we don’t share the same feelings, experiences or ideas.

**GOOD LUCK!**
Additional reading:

You can always find additional sources/content to share at meetings by visiting TLC’s Website http://www.bfrb.org/

Am I Ready to Start a Support Group?
http://www.bfrb.org/volunteer-get-involved/support-group/165-am-i-ready-to-start-a-support-group

12 Step Information Adapted for BFRBs:


Suggestions and Helpful Hints for a Support Group:
http://www.bfrb.org/volunteer-get-involved/support-group/166-suggestions-and-helpful-hints-for-a-support-group