These resources were created by many generous organizations willing to share their expertise with the broader peer support community. For questions about the resources please reach out to programs@childneurologyfoundation.org to receive more information.

Resources sorted by topic:

- Peer Support 101
  - Reports & Document from Peers for Progress (Links all on one page) ........................................ 4
    - Program Development Guide
    - Global Evidence for Peer Support: Humanizing Health Care
    - Peer Support in Health: Evidence to Action
    - Peer Support in the Patient-Centered Medical Home and Primary Care
    - Peers for Progress Grantee Program Profiles
    - Peers for Progress Peer-Reviewed Publications
    - Economic Analysis of Peer Support Programs
    - High Tech/Soft Touch: Integrating eHealth Into Peer Support
    - Designing Peer Support Programs for Older Adults with Diabetes
    - Solutions to Problems in Managing Peer Supporters
    - What is Peer Support?
    - Peer Support: A Day in the Life
    - Consultation for Peer Support Program Planning, Development, Quality Improvement, Expansion, and Research
      - Peer Support Best Practices Toolkit (Holland Bloorview Kids Rehabilitation Hospital) – link only

- People are the Priority - Selecting your Peer Support Specialists
  - Ambassador Registration Form (LGS Foundation) ................................................................. 5
  - Ambassador Agreement (UMDF) ................................................................. 6

- Training Your Peer Support Specialists
  - Peer Support Training Materials (LGS Foundation) ................................................................. 9

- Family Matching
  - Best Practice Timeline for Parent Support Match (Parent to Parent USA) ....................... 15

- Sustaining Your Dream Team
  - Self-Care Materials (LGS Foundation) .................................................................................. 16

- Building a Community
  - Promoting Peer Support on Social Media (Peers for Progress) ........................................... 18
  - Ambassador Organizational Chart (LGS Foundation) ......................................................... 20

- Developing Trusting Relationships with Physicians
  - Obtain Buy In (Peers for Progress) ...................................................................................... 21
  - Developing Trusting Relationships Doc (CNF) .................................................................... 23

- Expanding your Peer Support Program
  - Ambassador Program Overview (LGS Foundation) ............................................................. 26
Johns Hopkins School of Medicine has created a Peer Support Roadmap with a plethora of resources in many related topics. Visit their website and share your contact with them to receive access to the resources. Available resources are listed below:

- **Tools to Help Program Leaders Develop and Organize a Program**
  - Program policies and confidentiality policy (Beth Deaconess Medical center)
  - Creating an elevator speech (NAMI Maryland)
  - Mission statement (Stanford Peer2Peer)
  - Matching and first contact protocols
  - Matching endorsed evidence based and best practices
  - Permission for release of information to peer supporter template

- **Role Descriptions (for Peer Supporters and Program Coordinators)**
  - Peer Supporter role description
  - Program Coordinator job description

- **Recruitment Material for Peer Supporters**
  - Peer supporter recruitment brochure

- **Screening Tools for Peer Supporters**
  - Peer Supporter application and interview questions
  - Peer Supporter criteria
  - Guidance for recruiting screening and training peer supporters

- **Peer Supporter Training Material (Material from the Roadmap to Peer Support - Workshop on providing peer support)**
  - Sample Agenda
  - Core Skills and Competencies
  - Peer Supporter Training Workshop Slides
  - Peer Supporter Training Workshop - additional material
  - Pre and Post Training Workshop Survey

- **Recruitment Material for Program Participants**
  - Participant recruitment card
  - Request for peer support form
  - Participant recruitment brochure

- **Documentation Forms for Peer Supporters, During or After Support Activities**
  - Peer Supporter contact notes

- **Evaluation Forms**
  - Program Participant survey

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Child Neurology Foundation is not responsible for the content of any of the resources provided in this packet.
Thank you to our 2019 speakers:

**Brad Thompson, MA, LPC-S**  
Family Support & Empowerment Program, Peer Support  
Specialist Child Neurology Foundation

**Patrick Tang, MPH**  
Program Manager  
Peers for Progress

**Wendy Fry**  
Parent & Caregiver Engagement Director  
Dravet Syndrome Foundation

**Mary Anne Meskis**  
Executive Director  
Dravet Syndrome Foundation

**Hanan Aboumatar, MD, MPH**  
Associate Professor of Medicine and Public Health  
John Hopkins School of Medicine

**Marsha Quinn**  
Co Executive Director  
Parent to Parent

Thank You to our Believer Partners:

CNF gratefully acknowledges the 2019 Family Support & Empowerment Program (FSEP) partners:

Greenwich, Horizon, LivaNova, Novartis, UCB, and Ultragenyx
# Reports & Documents from Peers for Progress

## Major Reports and Guidance

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<td><em>Report from an International Conference</em></td>
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<td><em>US Conference addressing Advocacy, Practice and Dissemination</em></td>
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<td>Peers for Progress Grantee Program Profiles</td>
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## Topic-Specific Reports

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<td>Designing Peer Support Programs for Older Adults with Diabetes</td>
<td><a href="http://goo.gl/yQav9V">http://goo.gl/yQav9V</a></td>
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<td>Solutions to Problems in Managing Peer Supporters (Including low frequency of and response to errors, faulty counseling skills)</td>
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## Videos

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LGS Foundation Ambassador Program Registration Form

The Lennox Gastaut Syndrome Foundation (LGSF) Ambassador Program is designed to match individuals and families with others who are experiencing the same or similar challenges. The goal is to link individuals together who can provide experience-based information and support to one another. When you register with the LGSF Ambassador Program, your information will be used only for the purpose of this program.

Please complete this form as accurately as possible. Type or print clearly.

Your name: ____________________________________________

Your Mailing Address: ____________________________________________________________

City: ______________________________ State: _______ Zip/Postal Code: __________

Telephone and email information

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Name of Individual with LGS | Date of Birth | Age of LGS diagnosis in months or years | Relationship to individual with LGS: Parent, sibling, grandparent, legal guardian or other

Languages spoken other than English: __________________________________________________________

Consent

I, ______________________ agree to participate in the Lennox Gastaut Syndrome Foundation (LGSF) Ambassador Program. In signing below, I give my permission to the LGSF Ambassador Program to release my name to LGS families/caregivers. I will clearly communicate that I serve as a volunteer for the LGSF and my opinions and comments reflect my personal experience in the diagnosis, testing, and treatments only and are not that of the LGSF or medical professionals.

Signature: ____________________________________________ Date: ________________

(Typed name is acceptable)
UMDF Support Ambassadors are an important part of the UMDF’s Support Program. We are grateful for your interest in this Volunteer role.

* 1. I agree to be a United Mitochondrial Disease Foundation Ambassador from January 1, 2019 through January 1, 2020. I understand that the United Mitochondrial Disease Foundation (UMDF) will make referrals from the national office and will publicize my position as an Ambassador through newsletters, the web site, and occasional mailings.

This agreement must be renewed annually.

☐ I agree

2. Which role(s) are you most interested in?

☐ Support Ambassador

☐ Support Group Leader

Other (please specify)

* 3. As a UMDF Support Ambassador, I agree to the following:

- I agree to be a strong advocate of the UMDF and uphold the UMDF Mission in my role as an Ambassador: to promote research and education for the diagnosis, treatment, and cure of mitochondrial disorders and to provide support to affected individuals and families.
- I will respond to inquiries and I will do my best to respond within 3 days (with the exception of special circumstances such as illness, vacation, etc.) in regard to my selected role and will connect potential new members to the National office when appropriate.
- I will inform the UMDF of all fundraising events that I am planning, to ensure it aligns with the mission of the UMDF.
- I will keep all member information confidential including, but not limited to, names, telephone numbers, e-mails, and personal information that is shared with me.
- I understand that any lists I may receive with UMDF member information is the property of the UMDF and I will not use this information for purposes other than for the operation of UMDF meetings and/or activities.
- I will notify the UMDF in a timely manner if I am unable to continue as a UMDF Ambassador.

☐ I have read and understand the above requirements.
4. Check all categories in which you have personal experience and/or are comfortable networking with others:

- Parent of Child with Mitochondrial Disease (Age 0-18)
- Young Adult with Mitochondrial Disease (Age 18-35)
- Adult with Mitochondrial Disease (35+)
- Lost a loved one to Mitochondrial Disease
- Caregiver of Adult with Mitochondrial Disease
- Extended Family Member or Friend
- Other (please specify)

5. Indicate other areas where you have experience and are comfortable in addressing with others – check all that apply:

- General Support
- Tube Feeding
- TPN
- Medical Child Abuse
- Grief
- Social Security and/or Workplace Disability Issues
- Navigating Insurance Issues
- Transitioning
- IEP's
- Homeschooling
- Other (please specify)

6. The UMDF has my permission to provide my contact information to UMDF patients/families based on my areas of interest. Please include email address and preferred phone contact below.

- Agree

If different than the contact information below, please provide your PreferredEmail/Preferred Phone to release to patients/families:


7. I am fluent in the following languages.

8. Please share/update your contact information with us.

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PHRASES TO HELP LISTENERS BE “ON TARGET”

While you are “actively listening” to an individual on the phone, here are some suggested responses you can use during the conversation to let them know you are interested:

**Give Support**
"I sense that..." “That’s good.”
“So you think that...”
“You feel that...”
“So, your main concern at this time is...”

**Seek Information**
“What happened when...?”
“Let me see if I understand what has happened...”
“What did you think...?”
“How did you feel...?”

**Explore Alternatives**
“What else happened?”
“Any other thoughts?”
“Any other possible avenues?”

**WORDS TO AVOID**

‘Should, Shouldn’t’
“Should” and “shouldn’t” imply that the individual has options that may not exist. For example: saying, “You should put your child in a private school,” when the family may not be financially capable of doing that.

‘If I Were You...’
You are not that person. Example: “If I were you, I would put a stop to that situation.”

‘Don’t’
“Don’t worry” or “don’t feel angry/guilty/etc.” implies that you are capable of judging the situation.

‘Be Realistic’
Each person has the right to view their situation the way they perceive it. Support starts when you meet the other person at their “stop” on the journey.

‘I Know How You Feel’
You don’t know how they feel; you only know how you felt. You can use your experience by stating how you felt at a similar point in the process.

‘Oh, You Don’t Mean That’
They probably do mean it. It is their thoughts, their feelings, their situation and their life.

‘You’re Special’
This phrase puts a kind of burden on the individual. We all do our best depending on the situation and resources available at that moment.

When you talk, you are only repeating what you already know. But if you listen, you may learn something new.
— Dalai Lama
TECHNIQUES FOR PHONE OR SUPPORT GROUP INTERACTIONS

(Facilitated by Support Network volunteers)

Listening is an active process, requiring energy and effort to comprehend and remember what the individual is trying to communicate. A sympathetic listener will soon realize that listening can be healing and helpful. To become a better listener, try to apply the following rules.

ACTIVE LISTENING

1. Prepare to listen. Although only your ears are involved, it’s hard to effectively listen well while attending to something else. Give the other person your full attention. If you can’t, try to arrange a time with the caller when you can give them your fullest attention.

2. Listen to understand rather than to refute. Postpone your judgment of what the individual is saying and strive to ascertain what the person means.

3. Control your own emotions. If you find yourself reacting strongly to what is being said to you, try to put your own feelings aside for the time being.

RESPONDING AND CLARIFYING

1. Encourage the individual to express him or her self completely, by saying something like, “How did that make you feel?”

2. Help the individual to identify the essence of the problem or issue they are trying to discuss.

3. Paraphrasing, or restating what the individual said, can contribute to open communication. It lets the person know that you heard what was said and are trying to understand it. It also provides a check on the accuracy of your perception. An example of paraphrasing: The individual states, “I’m angry with the school system and Ms. Jones is an incompetent teacher.” Your response may be similar to this: “It sounds like you are angry with the school system and you feel that Ms. Jones is not a competent teacher?” Paraphrasing can lead to open dialogue by letting the individual know that you are listening and trying to understand.

SUMMARIZING

Summarizing is an attempt to condense and crystallize what the individual has stated. Summarizing at the close of the conversation will let the individual know you heard what was said, what the next step is and who is going to do what.
DO'S & DON'TS FOR PHONE OR SUPPORT GROUPS/MEET-UPS

THINGS TO DO:
1. Let them talk, and make sure you listen.
2. Direct the conversation by encouraging them to express their concerns and their questions.
3. Be open-minded and accepting of other’s feelings and attitudes.
4. Act as a peer and share only a few of your similar feelings, fears, apprehensions, experiences, etc.
5. Comment on positive steps that they have already taken.
6. Encourage individuals to take time out for themselves.
7. Form an alliance with them. Agree when you can and remain silent when you can’t. Example: The individual says, “Dr. ______ is wonderful.” Your response could be, “I understand a lot of parents are pleased with the care they receive from Dr. ________.”
8. Do allow the group or individual to vent their frustrations.

THINGS NOT TO DO:
1. Do not give medical advice. Example: “That is the wrong medication!”
2. Do not try to psychoanalyze.
3. Do not try to give final answers or solutions. Example: “You must do ________.”
4. Do not overpower them.
5. Do not criticize professionals, agencies or institutions of care.
6. Do not dump your problems on the group or the caller.
7. Do not take responsibility for other’s problems. It’s theirs.
8. Do not discuss your conversations with others to anyone else. Confidentially is a must!

UNLESS SOMEONE LIKE YOU CARES A WHOLE DAMNED LOT, NOTHING IS GOING TO GET BETTER. IT’S NOT.

- DR. MURI
NUTS & BOLTS OF FORMING A SUPPORT GROUP & FACILITATING THE MEETING

If there’s an issue or concern that people share, an opportunity exists for developing a support group. Peer support groups are usually inspirational types of groups. This means the members have a strong mutual identification and the group stresses positive elements. The group may be homogenous (having the same special need) or heterogeneous (having many different special needs) within a common category such as LGSS, a disability, IEPs, mental health issues, parenting, etc. As a facilitator or leader of such a group, you will need to have a few rules and skills to draw on.

1. Do not judge the success of the group by the turnout on any given date. It will vary, for known and unknown reasons. Don’t start the meeting with an apology for “who isn’t there.” Instead, warmly welcome those who have come, even if it is just one or two.

2. The group process tends to happen without a lot of intervention from the leader or anyone else. This is the beauty of it and is probably why it is so widely used and brings so many benefits to the participants. Just sharing and talking to “people who have been in your shoes” is beneficial.

3. Get the people there. Send your notices out at least four-six weeks in advance. Get a list of contacts from the LGSF and other volunteers. Post your notice at a physician’s office or therapy center. It’s important to remember that clinics and agencies, including the LGSF, are not permitted to release names without permission.

4. Be ready to greet participants. Have a sign-in sheet with space for addresses and phone numbers so that you can keep your mailing list accurate and current. Share any new addresses or changes in addresses with the LGSF. A sample sign-in sheet is provided at the back of this Guide. Have coffee and snacks available. Have comfortable seating in a social, interactive arrangement (a circle is best, if possible).

5. To get the group talking, ask people to introduce themselves. They should give their name, and their child’s name and a bit about him/her. The leader should go first to set the tone and also set the time limit for these introductions.

6. After the introductions, give a brief explanation of the purpose of the group as a reminder for old members and as clarification for new ones. For example, say, “The main purpose of our getting together is to give new members a chance to meet and talk with others who may have similar experiences. All information disclosed here remains confidential.”

7. The leader is not intended to be an “answer person.” When someone asks a question, the leader can say something like “Would anyone like to respond to Jane’s question?” Your job is to get the group involved in open discussions, keeping in mind that the healing and the answers come from the group, not you. As a part of the group, of course, you also generate discussion. Do not, however, put someone on the spot to speak. For example, “Susan, would you like to tell everyone how you would handle this situation?” Some people like to observe more than participate, especially if they’re new to the group.

8. Give the issue being discussed sufficient time, but move on, even if it may not be solved. You should not stay with one person’s issue all evening unless the entire group is finding it beneficial. “Are there
other things you’d like to talk about tonight?” Or, “How are things going for the rest of you?” Keep using open-ended questions that require more than a “yes” or “no” answer.

THE ROLE OF THE FACILITATOR

A Facilitator...

- is a neutral servant of the group.
- draws ideas from the group.
- focuses energy of the group to a common task.
- protects individuals and their ideas from attack.
- encourages everyone to participate.
- helps the group find win-win situations.
- keeps the group moving forward with the agenda.

As a facilitator, it is notable to be aware that there are three basic components for recovery from a life-altering event, such as a perceived loss, death and/or illness. The components are skills discussed previously in this manual, but worth mentioning again in the context of a peer support group. They are:

1. Being listened to by an empathetic person.
2. Having someone agree with you that, yes, this is a terrible thing that has happened.
3. Being allowed to help someone else who has had a similar experience.

Many lay facilitators have run successful groups for years. It is not difficult, although sometimes difficult people show up. Just gather people together and give them the opportunity to talk to each other.

PROBLEMS YOU MIGHT ENCOUNTER

The most frequent problem is having one person wishing to remain on center stage with their concerns and monopolizing, not letting others participate. First, realize that this is probably a person with a great deal of need. Try to totally focus on their issue for an adequate, but limited, amount of time (perhaps 5-7 minutes). Openly acknowledge the depth of the person’s pain and emotions. State that the group will not be able to solve it tonight, that you are glad she/he brought up the issue, and that everyone will be thinking about possible solutions.

Most of the time, solutions lie within the person experiencing this type of issue. As a leader you can say something like, “I’m sorry we haven’t been able to resolve this issue, but we do need to move on to another issue since others have given up their time to be here tonight. Perhaps you will be able to help them with their concerns. In doing so, you may find an answer for your issue.”

The group is having a hard time initiating conversation. You might talk about your own situation, joys or pain, or a combination thereof. As soon as someone else starts to share, let go of your issue and listen. You may want to repeat some of what the person has said in your own words, so that they know they have been heard and understood. It will also encourage others to talk more.
If the talk seems to be leading to an argument, try to diffuse it before it gains too much momentum. You might say, in a rather "take charge" voice, "I can see that there are multiple viewpoints in this very sensitive area. It's very important that this group respects all ideas and comments, even when they may not agree with them." Then, look to other members of the group and ask, "Who has another topic they'd like to discuss?"

Closing the meeting on time. The notice you posted before the meeting should include the closing time. People start to get restless if the meeting seems to be running overtime. About 15 minutes before the end of the meeting, make an announcement that it is about time for the meeting to end. Reminding the group of the time limit may also be useful when one person is monopolizing the meeting or when an argument is building. In such events you may interject with - "I just want to respect everyone's time. You've all gone to a great deal of trouble to be here and I'd like everyone to have an opportunity to be heard."

Remember, you are a peer facilitator. You are not expected to use professional counseling skills. Your main job is to get the group talking and to listen well. The group members are there to help each other work through their feelings or concerns. Sometimes these are issues they can't share, even with family members. Helping people through the grieving process and finding practical solutions for real problems are all part of the peer group process.

Some members may have questions that nobody is in a position to answer. In such events, have a pen and paper handy to note these questions and tell the group you'll contact someone at the foundation who may be able to answer that and get back to them.
P2P Best Practice Timeline for Parent Support Match

- Contact the referred parent within 24 to 48 hours
- Connect referred parent to supporting parent and/or requested resource(s)
- Follow up with the parent and supporting parent within 1 week
- A Total of 4 Contacts within the first 8 weeks of referral
- Evaluation call 8 weeks after match

24 to 48 hours • Match • 1 week • x4 contacts • 8 weeks
TIPS ON HOW TO BE GOOD TO YOURSELF

It's essential for an individual to attend to her/his needs before attending to the needs of others. The tips below on how to be good to yourself may prevent "burnout." The techniques and suggestions may also be valuable information to share with the individual contacting you whose life has been affected by LGS.

BUILD A STRONG FOUNDATION
1. Be good to yourself, because you deserve it! Know what you enjoy and safely indulge yourself. If you crave a long, hot bubble bath, give yourself that treat and enjoy.
2. Re-focus attention on things you like to do, people you like to spend time with and places you like to go.
3. Select a mantra or a word that can shift your attention. A mantra can be a prayer, song, or a word that brings comfort to your mind. An example of a comforting word is "peace."
4. Allow yourself to have and express feelings about the grief involved in your losses.
5. Practice living in the present. The future is not here yet, and yesterday can't be redone.
6. Make positive plans and begin to set concrete steps to translate those plans into action.
7. Take responsibility for your fate. Plan to feel good, to let go and to take care of yourself.
8. Forgive others. It might seem like you're doing the other person a big favor, but the person who benefits most from forgiveness is the "forgiver."
9. Be yourself; the self you thought you lost when you became immersed in the LGS world.
10. Allow yourself to grow, change and to succeed.
11. Give support to others and learn to accept it in return.
12. Set realistic expectations for yourself.
13. Express valid personal wants and needs.
14. Take responsibility for your thoughts and feelings by using "I" messages. An example of an "I" message is: "I'm feeling angry and overwhelmed about this situation."
15. Say "no" without feeling guilty. Say "yes" when you want to.
16. Prioritize the things you have to do.
17. Eat healthy and supplement if you need to.
18. Put yourself on the back for a job well done.
19. Visualize yourself being successful.
20. PLAN TO FEEL GOOD! Write your own horoscope and make it exciting and positive.

Self-Care is a priority and necessity - not a luxury - in the work that we do.
MANAGE YOUR STRESS

Numerous health experts have agreed that exercise can reduce stress, increase self-awareness and help build self-esteem.

Exercise can also:
1. Help prevent coronary disease and possibly other diseases
2. Delay the aging process
3. Improve breathing efficiency
4. Strengthen muscles, tendons and bones
5. Increase muscle flexibility, tone and reflexes
6. Increase endurance
7. Improve digestion
8. Increase energy and reduce depression and fatigue
9. Enhance physical appearance
10. Improve mental attitude and frame of mind
11. Improve thinking
12. Promote feeling of euphoria, tranquility and relaxation
13. Promote muscular relaxation
14. Provide a self-enhancing skill in a particular activity
15. Allow for easier and better sleeping
16. Provide an area for application of goal setting/achieving skills
Piloting Dissemination and Advocacy of Peer Support through Social Media: Peers for Progress Recent Effort and Lessons Learned

Social media tools provide opportunities to advance dissemination and advocacy of peer support. However, peer support programs and organizations can benefit from understanding how to use these tools in order to produce intended impact. Coinciding with the recent launch of our new website (http://www.peersforprogress.org), Peers for Progress has also made a concerted effort to increase our social media presence. This article highlights our recent effort piloting social media strategies, as well as shares initial lessons learned.

As outlined in the CDC’s guide to social media writing, we hope to take advantage of these social media tools to “expand our reach, foster engagement, and increase access to credible, science-based health messages.” Peers for Progress has chosen to focus on blogging and Facebook to present two different kinds of information. Facebook allows us to highlight local, national and international news stories related to peer support, funding opportunities published online and links to academic reports and presentations produced by other organizations and institutions. These stories are generally posted to draw attention and commentary and allow our followers to get a complete story by following the link.

Blogging offers us an opportunity to develop our own unique content, express commentary on issues in the field of peer support, and provides a venue to comment on current topics in a format that allows quick publication. Compared to Facebook, blogs provide a more in depth look at peer support topics and issues and often cite a number of external news sources as part of a larger discussion.

In an effort to take advantage of these outlets to engage those interested in peer support, we have dramatically increased posts on the Peers for Progress Facebook page and the Peers for Progress Idea Exchange Blog. Instead of one monthly post on the Facebook and occasional posts on the Blog, we are maintaining a minimum of 3 stories of interest per week on Facebook, and one article per week on the Blog. We also encourage our Grantees, Global Network Members and others interested in peer support to engage and contribute to this effort such as “liking” our Facebook Page and writing Blogs. For example, Maurits van Pelt, Director of MoPo Tsyo Patient Information Centre in Cambodia, wrote a 3 part series on integration and sustainability of peer support programs.
Initial lessons learned have emerged throughout this process:

- Our Facebook page has turned out to be a great way to cultivate workforce development by engaging young professionals to share their experiences as new workers in peer support research and practice. For example, recent posts highlighted blogs written by two Masters students currently working on peer support with Village Health Workers in Thailand. By using the Facebook medium, we were able to make an entire new audience aware of the experiences of our students and gained many new graduate student followers. Further engagement between current students and recent graduates provides an avenue for organizations and research projects to connect for potential employment and volunteer experiences.

- Identifying interests of our target audiences is really important for expanding our “reach”. Recognizing that many programs and organizations utilizing peer support approaches are under the radar, we intend to include a wide variety of topics in order to get their attention. For example, we have featured commentaries on the Affordable Care Act on the Facebook Page, and used the Blog to dissect peer support and community health workers policy in the US.

- It is noted that maintaining a social media presence requires ongoing dedicated staff time. By consistently finding and sharing content that is of interest to our readers, Peers for Progress gains increased exposure beyond an initial group of fans. If a story become very popular and is shared by users, friends of friends on Facebook see our stories appear in their newsfeed. Since graduate students, researchers and project managers often have some friends with similar vocations and interests, this represents an opportunity to increase our audience and support for peer support programs at an international level.

- Although information on how to use social media to most benefit an organization are beyond the scope of this spotlight, several resources are available on the web. We recommend exploring the Community Tool Box’s guide to “using social media for digital advocacy”, “10 tips for using non-profits on Facebook” and the CDC’s social media guidelines and best practices.

Overall, our increased focus on Facebook and blogging gives Peers for Progress another opportunity to accomplish our mission goals of promoting peer support as a key part of health, health care, and prevention around the world and accelerating the availability of best practices in peer support. As we are still learning how to better our approaches, we encourage our readers and affiliates to help us with this process by sharing your suggestions/experience, as well as following and contributing to our Idea Exchange Blog and Facebook page.
Obtain Buy-In

The importance of obtaining “buy-in” for a peer support program cannot be overstated. While there may be many people in your organization that support the use of peer specialists in your programs, others may have concerns. Some typical concerns include:

- **Potential risk for relapse** – Some individuals may be concerned about potential relapse for peer specialists. They may possess conscious and unconscious biases that contribute to stigma and associated resistance. There can be questions as to whether a peer specialist can handle the demands of the job.

- **Ability and skills** – There may be concerns about the competence of peer workers, particularly if they play a role in peer education and treatment. Since many peer workers do not have advanced education and degrees, there could be questions about their knowledge, skills, and ability to work with their peers.

- **Competition for resources** – Some providers or clinicians may be concerned about being replaced by peer workers who may be able to provide some of the same services at a lower cost to the organization. Also, in a setting with limited resources, hiring peer workers may be viewed as an unnecessary expense or the first position to be cut if a reduction in the workforce needs to be made.

To address these concerns and others that may arise at your organization, it is helpful to develop a clear message about why your organization is implementing a peer support program; include a statement of support from leadership and include information about the perceived benefits of the program. You will want to communicate your message clearly and consistently. Provide education and information to staff about the effectiveness of peer programs.

Peerspecialists are equally as effective as other healthcare providers at stabilizing clients\(^3\) and perhaps more effective at quickly engaging clients who are most resistant and/or alienated from the healthcare system.\(^5\)
Answer these questions to help pinpoint why you believe that implementing a peer support program will benefit your organization.

1) What are the reasons your organization is considering a peer support program?

__________________________________________________________________________

__________________________________________________________________________

2) Pick the two most important reasons. List them here and describe why they’re important.

__________________________________________________________________________

__________________________________________________________________________

3) How does implementing a peer support program benefit your organization?

__________________________________________________________________________

__________________________________________________________________________

4) What makes the implementation of a peer support program personally relevant to you?

__________________________________________________________________________

__________________________________________________________________________

Create a statement that incorporates your responses to the questions above. This statement will help you to develop a clear, concise message explaining why your organization is implementing a peer support program.

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
Developing Trusting Relationships with Physicians

If your organization wants to collaborate with physicians, the first step is to create trusting relationships.

Once you have this trust, you can count on the physician to promote your organization, distribute your materials, or provide expert opinion when needed.

What is Trust?

Trust is built and maintained by many small actions over time.

In his 1993 dissertation, "A Construct of Trust" Dr. Duane C. Tway, Jr. Explains trust is constructed of three components:

1. The capacity for trusting: Some doctors may not trust people by default, or maybe they have been misled in the past. If a doctor has dealt with an “irrational” parent or adversarial group in the past, they will have diminished capacity for trust. Find out what the physician needs to feel he can trust your organization. Maybe ask about other partnerships that have been effective.

2. The perception of competence: Doctors need to know you understand the needs of families dealing with the condition you are providing support for. They need to know you understand the principals for peer support. You need to convince them your group/people are trained differently and promote healthy relationships and mutual respect that value the different expertise that each person brings to the relationship in their role. They need to know that you only provide “peer support” and not medical advice. They particularly need to know that you only promote/discuss medically proven treatments or therapies. In peer support, it is a “fireable” offense to question a doctor’s treatment plan or bedside manner. It is very OK to encourage the caregiver to ask more questions of the doctor, schedule a consult, etc., but to offer your own “2nd opinion” is unacceptable. For the medical community to accept us and use our unique skill sets they have to trust us to be as much a part of their team as we are the family’s team.

3. The perception of intentions: Doctors need to feel confident that the actions, words, direction, mission, or decisions of your organizations are motivated by mutually-serving rather than self-serving motives. i.e.: if your website bashes doctors for not understanding families – how likely are they to believe that your organization will help families go to doctors to get the medical treatment they need. You organization can certainly advocate for families on your own in a way that is in accordance with your values, but if you want them to refer to you, they have to see you as supporting them as well.

8 Ways to Build Trust in Physician Partnerships

1. Prove Your Value with Quick Wins Up Front

Develop an “elevator pitch” to quickly demonstrate what your organization does for families. Show what your programs can do for families and other doctors... testimonials from families and peers are great!

2. Be Selfless and Serve as a Resource

How does your program help the doctor – Does it save them time during visits? Does it empower treatment compliance? Does it answer questions the doctor may not be able or have time to answer? Do you have online or other resources they can share with families? (i.e.: guide to selecting a Seizure Alert Device”

3. Speak Candidly About Your Goals

Be candid about your goals. Beating around the bush implies dishonesty, at which point the partnership won’t be fully successful for anyone. Reinforce your intent with actions. (If you say you will follow up with an email – do it!) Expose a vulnerability to show you have viable reasons for courting a partnership with this doctor. (Let them know you recognize them as the expert and you need their insight or direction on your initiatives.)

4. Define Roles and Responsibilities

Partnerships are typically made when two parties believe that each other’s services will be mutually beneficial, or when they’re focused on a common goal. Where partnerships sometimes fall apart is when the parties don’t discuss and align on roles and responsibilities. It’s important to determine this upfront so that it’s clear what the expected outcomes. Do you want this doctor to serve on your board as an advisor, or do you just want him to help distribute materials? What exactly will you do when they refer a family?

5. Prioritize Transparency

Successful partnerships are built by having open and honest discussions with your potential partner. If you have concerns about how some doctors are addressing an issue, express those concerns in a non-confrontational way. If you don’t know something, don’t fake.

6. Enter A Referral Agreement (if appropriate)

Will you promote a specific doctor as an expert, or recommend his practice to families? Will you tell the doctor how many of his families utilize your services? Will you share concerns you hear from families (without providing specific identifying information?)

7. Follow Through on Promises

Follow up with the doctor and let him know about your successes. How has your work helped families?

8. Take Your Time

The most successful and mutually beneficial partnerships are built upon a relationship that is fostered over time. It may take a several interactions before a doctor consistently promotes your program. If you are a new organization, or new to peer support, a provider may want to see you prove yourself and your commitment to stay in the game. Several organizations start very eager, but as resources and energy fades, the organizations tend to fade as well.

Lennox Gastaut Syndrome Foundation - Ambassador Program Overview

The definition of an Ambassador: A person who acts as a representative or promoter of a specified activity.

The Lennox Gastaut Syndrome Foundation (LGSF) Ambassador Program is an informal, yet structured, group of empowered and caring volunteers who work closely with the LGSF. Our goal is to facilitate local connections, raise revenue and increase awareness while supporting the LGSF mission To improve the lives of individuals affected by Lennox-Gastaut Syndrome through research, family support programs, and education. LGSF ambassadors foster links between LGSF, communities and individuals across the country.

The LGSF Ambassador program emphasis is on ‘local’. LGSF Ambassadors bring knowledge of specific needs in their respective community while furthering the LGSF mission and delivering the organization’s programs and services at a local level.

**Purpose**

LGSF Ambassadors are committed to building a stronger LGS community by supporting families and the quality of life for individuals with LGS through:

- **Fundraising** - for research into the cause, management and care for those with LGS through the LGSF research programs
- **Support programs** - providing families access to support services, resources and healthcare
- **Meet-ups** - professionals engaged in diagnosis, treatment and management of LGS
- **to connect families locally and build a stronger LGS community.** [www.meetup.com](http://www.meetup.com)
- **Education** for families and community around a variety of issues such as school-related concerns, transitions, ongoing research updates, etc... Ambassadors are urged to participate in ongoing webinars and update local families on upcoming educational opportunities.
- **Collaboration** with LGSF to assist families seeking advocacy in the areas of school services, housing, employment, independent living, healthcare
- **Awareness** – build the LGS profile and increase community support
- **Outreach** to community of aging parents caring for adult children with LGS

**Meetings**

State Ambassadors will meet quarterly. The purpose of the meeting is to inform and update members on upcoming support, education and advocacy opportunities as well as resource sharing and brainstorming. Members will be notified at least a month in advance of the date and time of meeting.
AMBASSADOR PROGRAM DIRECTOR

The responsibilities of the Ambassador Program director are as follows:

To provide one-on-one support to those who contact the LGSF seeking a connection to their local area and resources. The director is responsible for completing intake and documenting the information in the foundation database. The director acts as the point of contact for individuals and families seeking more information on local services and LGSF programs. The director is the liaison between the LGSF and state ambassadors. The director will coordinate quarterly meetings with state ambassadors.

Other responsibilities of Ambassador Program Director include:

- Management of the Ambassador Program facebook page
- Participation in LGSF planning calls with leadership
- Regular contact with Director of Family Support Services and Executive Director.

AMBASSADOR PROGRAM POSITIONS

The goals of the Ambassador Program are attained through the generous and compassionate support of local volunteers. These are unpaid positions supported and managed through the LGS Foundation. The structure of each regional area in the program may differ depending on local needs, strengths and desires of the community. In general, it is recommended the following roles be filled in each regional area to maximize the opportunity and attainment of the Ambassador Program mission and goals.

REGIONAL COORDINATOR

Our states have been divided into four Regions. A Regional Coordinator will be assigned to a group of states with each region having approximately 10-15 states. The Ambassador Program Director will provide support to the Regional Coordinators. The Regional Coordinator will provide Team Building support for the State Ambassadors within a smaller region with a focus on identifying new ambassadors, assisting in the launch of new programs, being a liaison for industry and local support programs, and encouraging involvement of the State Ambassadors. The Reginal Coordinator(s) will attend quarterly calls with the Ambassador Program Director. They will also host calls with the State Ambassadors in their region as needed.


Central Regional area - Missouri, Nebraska, Kansas, Minnesota, Indiana, Michigan, Illinois, Iowa, South Dakota, North Dakota & Wisconsin.

Southern Regional area - Florida, Oklahoma, Georgia, Texas, Arkansas, Louisiana, Mississippi, Alabama, Tennessee, North Carolina & South Carolina.

Western Regional area - California, Colorado, Arizona, Nevada, Idaho, Oregon, Washington, Wyoming, Montana, Utah, Alaska & Hawaii
• Terms of Service - The terms of service for a State Ambassador is two (2) years. State Ambassadors may choose to renew their commitment at the conclusion of their terms.
• Compensation - LGSF Regional Coordinators serve without compensation.

STATE AMBASSADOR

Each state will have at least one ambassador, sometimes more, depending on the size of the geographic area. Upon receipt of referrals made by the Ambassador Program Director, the state ambassador will make contact within 48 hours. The State Ambassador will provide one-on-one support, mentorship, systems navigation and resource sharing with local families. The State Ambassador will organize social activities, support groups and fundraising events. (see PURPOSE). The State Ambassador(s) will attend quarterly calls with the Ambassador Program Director.

• Terms of Service - The terms of service for a State Ambassador is two (2) years. State Ambassadors may choose to renew their commitment at the conclusion of their terms.
• Compensation - LGSF State Ambassadors serve without compensation.

*EDUCATIONAL LIAISON

The educational liaison will be responsible for contacting the Parent Training and Information (PTI) Centers in their state or region. They will provide the PTI Centers with a packet (provided by the foundation) of information and an introductory letter introducing themselves and the LGS Ambassador Program. PTIs provide parents/caregivers with free trainings, advocacy and information on special education. This will open the door for the educational liaison to connect families to the OTI Center’s trainings and supports in the area of educational advocacy. It will be the education liaison’s task to build relationships with at least one contact person at each PTI. This position is supported by the Director of Family Support Services who is responsible to educate the educational liaison in IDEA, 504, ADA (as needed) and government legislation advocacy as it relates to educational (such as the reauthorization of IDEA). The Educational Liaison will attend quarterly calls with the regional team.

*SPECIAL EVENTS CHAIR

The special events chair is responsible for organizing special events in the local community to raise funds for the LGSF. The funds generated by special events are integral to the organization’s mission to improve the lives of individuals with Lennox-Gastaut Syndrome through research, family support programs and education. The Special Events Chair will attend quarterly calls with the regional team.

*The membership of the LGSF is rapidly growing however many states are still without representation. In the early stages of the Ambassador program it’s expected that many of the designated positions will be performed by one or two individuals. Over time, as the program grows, the LGSF anticipates that these positions will be filled. New Ambassadors will be provided online training. Ambassador meetings/training updates will be provided at the LGS Family Conference every 18 months. *
AMBASSADOR PROGRAM COMMITTEES

All Ambassadors are encouraged to participate on established committees. At present, the existing committees are:

- The Newly Diagnosed/New to LGS
- Bereavement Committee
- Hispanic Outreach
- LGS Awareness
- National Fundraising
- Communications Committee

Each Committee will have a Chair and Co-Chair. The Chair will coordinate and facilitate regular planning calls as well as setting the agenda. The Co-Chair will assist the chair and, in the absence of the chair, the Co-Chair will facilitate the planning meetings.

*Future positions to develop as more ambassadors join the program.

The Lennox Gastaut Syndrome Foundation wishes to thank the TSA Community Alliance for sharing their resources in developing this manual.