



RARE TOOLKITS™

Support Groups:

A RARE Advocate's Guide to Connection








"A rising tide lifts all the boats"

Table of Contents

So You Want to Build A Support Group for Your Community	04
If You Build It They Will Come	05
Self-Check Interactive: Swing for the Fences	06
Lighthouse in the Harbor	07
Lauren’s Story	08
Geese & Groupies	09
Self-Check Interactive: Prepare for Take-Off	09
Types of Groups	10
Internet Sensation!	11
Group Dynamics	12
You’re the Captain Now!	14
Current Situation	15
How to Lead Online	18
Surviving Stormy Seas: Conflicts & Resolutions	20
It’s Show Time!	22
Standing Room Only	24
Marketing Interactive	25
Welcome to Something Bigger	26
Caroline’s Story	27
Let’s Stay Connected!	29

 *This magnifying glass is an indicator of numbered research information*

 *These little glasses indicate a bulleted list of tips and information*

 *Paper and pen indicate an interactive exercise*

So you want to build a support group for your community?



Thank you for including us on your journey! Most likely you have a need for this toolkit Support Groups: A RARE Advocate's Guide to Connection because you or a loved one has a rare disease. As you prepare to use the tools in this kit, we want you to know that you are not alone. We are in this together. It is our hope that the personal stories, resources, tips, and suggestions for self-reflection in this guide will make the road to advocacy for your rare disease more manageable.

We know, all too well, that a lack of information and support for people living with RARE diseases can lead to feelings of dis-ease. Please know, it's not just you— you can feel depressed, anxious, and isolated and it's common in the RARE community. Fortunately, RARE Advocates see these challenges as opportunities to take control back from their disease by filling the void with support groups, knowledge, and advocacy.

While we believe you will benefit from reading all of the material in this toolkit, we don't want to overwhelm you. The articles do not have to be read in order. We've included a table of contents to make it convenient for you to find the information you are most interested in at this time. ■



If You Build It They Will Come

In the popular film *Field of Dreams* the lead character, Ray Kinsella, played by actor Kevin Costner, is on an unusual mission. He is determined to build a baseball field on his Iowa farm because of a mysterious voice in his cornfield that urges him on with the puzzling assertion, "If you build it, they will come."

Here on the big screen of real life, it's likely your motivation for starting a support group does not include a mysterious cornfield or Kevin Costner; but if it does, we'd love to hear about it! Otherwise, whatever your motivation is for starting a support group, we applaud you.

There are many things to consider as it relates to starting a RARE support group. Some of the information in this toolkit will likely be familiar to you. While, other information is more specific to the protocols of being a RARE support group facilitator. So, if like Ray Kinsella, you're motivated to "build it," this article is a good place to start.

"You will know you are ready to start a support group because you will be far along enough in your own journey to know what is in front and behind you"

-Anne Leserman, LCSW, Assistant Director of Community Services, Huntington's Disease Society of America

The Playing Field



Listed are some of the benefits of starting a support group for a rare disease community:

- The creation of advocacy initiatives
- Discovering new information about a rare disease
- Opportunities to educate and expand awareness
- Networking opportunities for your group members
- Community involvement and support

There is not one specific model for a support group, and they come in a variety of forms. While some support groups are created for a particular purpose or goal, rare disease support groups serve a unique purpose.

What makes a rare disease support group unique is the mission to serve every link in the chain

connected to the disease. Typically, the chain includes the patient, family members, friends, and caregivers. RARE support groups also assist the larger community through awareness and advocacy. Community response shows that support groups function as well online as they do in-person, it just depends on the specific disease.



Self-Check Interactive: Swing for the Fences

In the beginning the success of your group largely lies with you. If you are not emotionally ready or your other daily life commitments are rigid, this may not be the best time for you to start a support group. Listed are some key questions to help you determine if you are ready to swing for the fences and cross home plate! There are no right or wrong answers to the questions.

Why do I want to start my own support group?

Importance: It is helpful to understand what your motivations are and to evaluate whether they are self-focused or for the greater good.

What is the goal or purpose of my group?

Importance: This answer will help you establish a goal for the group and also help keep you on task as you recruit participants, deliver resources, and facilitate meetings.

Where am I in my own journey?

Importance: If you are currently not in a good place about this medical journey, can you successfully support others at this time? What a "good place" means is very much a personal experience.

Am I ready to take on this responsibility?

Importance: Consider your current commitments to work, school, family, or place of worship. Are you willing to scale back any of these commitments to develop and facilitate a support group?

What are the financial costs for facilitating a support group?

Importance: Printed materials, guest speakers, snacks, website hosting or gratuities for the use of a meeting room are some of the potential costs of facilitating a support group. Are you able to and/or willing to pay for these expenses?

Deciding to start a support group takes time, responsibility, commitment, and dedication. It is critical to consider your overall health, emotional state, and physical abilities before you commit to starting a group.

Who's on First?

Before you take to the field, you should know if another group for your rare disease already exist. Within a small community, a duplication of efforts is not encouraged.



While it may feel like a hassle, doing a little research can go a long way. Here is a short list of questions you should, ideally, have the answers to:

1. Are there others in your area who are in need of your specific support group?
2. What resources and support currently exist?
3. How can you build upon those resources?
4. Is there a gap that needs to be filled?
5. Online or in-person—which platform is the most practical for your group?

Once you know what is available to you and your community, the next practical step is to decide if you are emotionally and physically ready to commit to facilitating a support group. ■

Starting a Support Group: Resources

A Guide to Starting a Patient Support Group

http://www.igliving.com/magazine/articles/IGL_2015-12_AR_A-Guide-to-Starting-a-Patient-Support-Group.pdf
This article by Abbie Cornett discusses how to start a support group. It covers basics such as defining goals, picking a forum and marketing.

Considering starting your own support group?

<http://fpiesfoundation.org/starting-your-own-support-group/#Finding the Perfect Fit>

A guide produced by the FPIES Foundation on a variety of support group models used within their rare disease community as well as tips on running a group and extra resources related to support groups.

Creating and Facilitating Peer Support Group <http://ctb.ku.edu/en/table-of-contents/implement/enhancing-support/peer-support-groups/main>

Community tool box is a health resource. They provide several chapters on support groups, including this chapter series which discusses the process of beginning a support group including: Why? What kind of support group? And How to lead your peers.

How to Create Facebook Community Guidelines <https://www.socialfresh.com/facebook-fan-page-community-guidelines/>

Social fresh is an online forum that discusses social media usage and tactics. This resource provides tips on how to start your own Facebook group and contains some example guidelines and rules for your Facebook group or community.

Lighthouse in the Harbor

Starting a support group can make you the lighthouse in the harbor to others searching for a better place on their own journey. While you will benefit from being a member of the group, it is important to remember your primary role is facilitator.

"Starting a support group for your rare disease is like building a light house for your community. It helps those who need guidance and it serves as a beacon of hope for when they feel lost"- Mary Jo Strobel, Executive Director, American Partnership for Eosinophilic Disorders (AFPED)

It is common for patients and caregivers to have different reasons for starting a support group.



Put a check mark next to the reason(s) you identify with.

1. Providing social and emotional support for members
2. Creating educational opportunities for patients and providers
3. Raising awareness about the RARE disease

Use this space to add other reasons that reflect your desire to start a support group.

"One of the greatest benefits of a support group is to become self-empowered and advocate for yourself and your group. When you first get diagnosed with a rare disease, it feels as though you have lost all control of your life, but going to a support group and sharing your feelings, your story, and gaining knowledge of others living with the same disease, you feel like you can gain some of that control back. That is what's important."

– Marc Yale, Senior Peer Health Coach, International Pemphigus & Pemphigoid Foundation

Starting a support group benefits the facilitator (whether a patient or a caregiver), group members, and hopefully your larger rare disease community. How your group will benefit is mostly dependent upon setting realistic goals and appropriate facilitation.

- 63 Some of the benefits reported by other groups are:
- Increased access to resources to hospitals, doctors, researchers, clinical trials, and/or therapies.
 - Improved understanding of the rare disease
 - Information about current and/or developing research, and other medical information
 - Increased public awareness about the disease and its community
 - Heighten empowerment of patient and caregiver advocates
 - Boosted social and emotional support amongst the community
 - Reduced feelings of isolation

The desire for privacy is often an issue when it comes to sharing information about your disease with others. But, if people in your immediate circle know about your need to start a support group you may get some help with your mission. "My mission in life is not merely to survive, but to thrive and to do so with some passion, some compassion, some humor, and some style." - Maya Angelou ■

Support Group Benefits: Resources

6 Benefits of Group Therapy <http://www.everydayhealth.com/news/benefits-group-therapy-mental-health-treatment/> Everyday health is a communication platform encouraging a healthier lifestyle, this includes emotional and mental health. Here you can find articles that encourage support groups and the benefits they can bring to those experiencing life crisis or chronic conditions.

Psychotherapy: Understanding Group Therapy <http://www.apa.org/helpcenter/group-therapy.aspx> American Psychology Association offers information on support groups, including the benefits, group types, joining a group and expectations.

Support Groups: Make Connections, Get Help <http://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/support-groups/art-20044655> The Mayo Clinic offers guidance in information on the benefits of starting a support group and where to find support groups for your population.

Lauren's Story

When I was a newly diagnosed patient, I wanted to find others who had the same diagnosis. I had been diagnosed with postural orthostatic tachycardia syndrome (POTS), which is not a rare disease, but shares many features with rare diseases because it is not well-known, there is no FDA approved treatment, and there is little government funding for POTS research.

I wanted to connect with other patients to ask them about their symptoms, what treatments helped them, and what doctors they were seeing. When I found an online support group with 2,000 POTS patients it was like hitting the jackpot. Everyone was so supportive and they could relate to what I was going through. Six years later, the group has grown to over 14,000 members. Several of the group members banded together to form a non-profit (Dysautonomia International). We're funding physician education programs, patient empowerment projects, awareness events, legislative policy meetings, and pushing the research forward so we can find better treatments for POTS as soon as possible.

If I can give advice to others starting out on this journey, collaborate with others and be informed about your community. Realize that other patients may not have the same experiences as you, even if you have the same diagnosis. Welcome people with a diversity of backgrounds and experience into your group. Always remember that you are in the same boat, even if some of you can paddle faster than others, and some of you may not be able to paddle at all. That's why you are there to support each other! By working together, you will be able to paddle that boat through the rough waters ahead, and you might meet wonderful new friends along the way.

-Lauren Styles, Patient Advocate

Geese & Groupies

A gaggle is a group of people or geese, no matter the number, who share a common task, goal, experience or relationship (or, in the case of geese, a common flight path) who meet either in-person or online. And, like a gaggle of geese you won't find two identical groups. Even if other groups share the same goal or purpose, the members in each group create a unique culture and dynamic based on their individual journeys.

As a group facilitator you may not aspire to boy-band-groupie status, but it helps to be approachable. Potential members will expect you to be informed about your disease. They will also expect you to have resources available to share with them. ■

Self-Check Interactive: Prepare for Take-Off

1. Have a clear purpose
The purpose of my group is:
2. Establish goals
My top three goals are:
3. Set realistic expectations for the group
One of my top expectations for the group is:





Types of Groups

Groups can either be open or closed. Each group type has its own set of benefits and challenges.

Open groups: This is an ongoing group that is open to new or existing members at any time. This option allows more flexibility for its members.

Closed groups: This group is usually offered in sessions or for a set duration. Group members need to be part of the group from the beginning.

Subgroups or Specialties

If there is a big demand for a group it can be divided into subgroups or target specific populations within the rare disease community. A few examples of potential subgroup types are :



1. Region or location
2. Age groups
3. At-risk
4. Siblings
5. Caregivers
6. Parents
7. Patients
8. Any person affected by the disease (friends, partners, siblings, roommates, etc.)

Be on Purpose

Groups will have a focus or main purpose. There are also hybrid groups or mixed groups; these groups often have more than a single focus. A group can have a variety of purposes and may shift its focus from meeting to meeting.



Common areas of focus and/or purpose for groups are:

- Social and emotional support
- Education
- Awareness
- Resources and networking

Knowledge is Power

In literary circles there is disagreement over the origins of the quote “knowledge is power.” Maybe Sir Francis (Kevin-LOL) Bacon used it first, maybe he didn’t; either way, knowledge certainly is power to rare patients and their caregivers. If you choose education as the focus of your group, you should be able to provide basic information (where available) about your disease and have a baseline understanding of the disease’s mechanism. Sharing this knowledge can go a long way in building trust and confidence with group members.

Listed are resources you can share with members.

- Newsletters
- PowerPoint slides on the basics of the rare disease
- Local foundations
- Medical resources (i.e. genetic counselors, counselors)
- Miscellaneous (i.e. medical insurance, clinical trials, advocacy efforts) ■

Internet Sensation!

Through the internet you can reach potential group members around the globe.

“When I first became ill, the world got so small. Weeks would go by without really talking to anyone, but starting a group on Facebook created this whole community out there that keeps me from being isolated. These people, without physically knowing them, are your friends.”- Tiffany Early, Patient Advocate



Many of the benefits of an in-person group and an online group are similar; but there are some benefits you can only get with an online group such as:

1. Because rare disease is RARE, there may not be enough patients with the same disease in a geographic area to form an in-person group. Forming an online group allows you to find members beyond your location.
2. Patients with Internet access can find your group from most anywhere.
3. You can extend your support network and to exchange stories with others experiencing similar challenges.
4. Community members can share their medical experiences and their medical network of support online.

Additionally, online support groups offer members:

Access Members unable to travel due to physical or financial hardships can participate from home.

Convenience Members are able to participate how and when they want. Online groups are available 24 hours a day, seven days a week.

Flexibility Members can participate as much or as little as they want. One person may only want to find other people with the same rare disease while another may want to engage further by sharing or asking questions of other members.

It was mentioned earlier that support groups can have a singular or hybrid focus, but online support groups have multiple goals. Many online groups are a source for social support, networking and resources, advocacy efforts, and for building awareness. An online group can be ideal for building a coalition and showing the effects of your specific disease. ■



Group Dynamics

Reality TV shows offer many examples of group dynamics, often, in crisis mode to keep viewers tuning in for the next meltdown. In a group setting, dynamics refers to the natural response and interactions that develop between group members.

When the group is newly formed members come together with a specific goal or purpose in mind. Overtime, members form relationships with each other and the group's identity and dynamics continue to evolve.

As a facilitator of a group it is important to encourage positive attitudes amongst members and cohesiveness within the group. This is particularly true if it is an open group where new members can join more frequently. Ideally, all members will make newcomers feel welcome, accepted, and safe.

Central Casting

As members join your support group there is a natural tendency for them to gravitate toward specific roles within the group. As a facilitator you need to be aware of these roles. Some roles are accompanied by personality traits and/or behaviors that may be challenging to you and/or other group members. If this should happen, it helps to remember that people take on roles based

on their needs, fears, and feelings of vulnerability. It is your responsibility as a leader to help a member to explore these feelings within the group and to build a supportive culture around them. The roles' chart highlights the more common roles people take on within a group. Other roles exist and may present themselves based on their group function. Additionally, these roles are commonly seen amongst in-person support groups where there is direct interaction between members, but they can also manifest in online groups.

Depending on the platform you choose for your group, you will approach these individuals differently. Regardless of the platform, the goals and purpose of the group are your top priorities. If you have these encounters remember it is not your charge to change members or the roles they assume. Your responsibilities are to help facilitate meetings and to build a positive group dynamic. ■

Roles	Description
Information Seeker	Search or request information, make suggestions, or have ideas
Expert	Offers or provides information, opinions, suggestions, or ideas
Encourager/Energizer	Affirms and encourages contributions of others
Follower	Listens rather than contributes, will take in and accept what others say without providing his or her own thought, opinion, or idea
Challenging Roles	Description
Dominator	Dominates conversation, has a rigid or narrow point of view and opinion on topics
Blocker	Changes topic, suppresses conversations and emotions
Critic	Reduces members' feelings or opinions
Clown	Can distract group members by bringing attention to him or herself. This role can be turned into a positive role if utilized by the facilitator properly

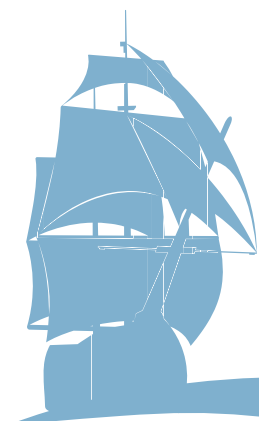
You're the Captain Now!

Whether you're at the helm of a cruise ship or alone in a rowboat—you're the captain and it is your nautical duty to keep the boat afloat! No matter which platform you use for your support group, in-person or online, the qualities of a successful leader are the same.

The members in your support group will expect you to be a good role model and to set the tone for the group. Desirable traits for a facilitator include being empathetic, respectful, inclusive, and non-judgmental toward all members of your group and to encourage the same behaviors of your members. Listening is important! You can zone out when the boss is ranting or when the kids are whining; but you have to be an active listener with your support group. It is also important to be observant of how group members interact with each other.

There is likely to be the occasion when a member will be challenging to either your or to another member, and you'll need to be ready to manage these situations. As the facilitator your priority is to keep members focused on the group's goals and purposes.

Facilitating your group should not be like wrangling cats. There are some basic principles for how to lead a group. First, you want to build rapport and trust within the group. You want the group to grow, and to create a vibrant and unique culture for the members. Your group should be guided by rules, goals, and a purpose. As the leader, you should feel empowered and ready to enforce the rules when necessary.



"As a group leader you will want to pay attention and be aware of each group member, their behavior and interactions. Take it upon yourself to become more educated so that you know what to look for."

- Cheryl Sullivan, Parent and Caregiver Advocate, Huntington's disease Society of America

Some days it is hard to communicate with your spouse, parents, or the barista who's taken your same coffee order for 10 years. Like other important people in your life, especially the barista, there may be times when it will be difficult to communicate with some group members.

Although you and your crew are likely experiencing a similar journey, you are also their captain. You may have to adjust your communication style to help your members and to push your group toward its goal. The chart shows techniques that can help you to become an effective support group leader.

Current Situation

As a facilitator you will want to pay attention to each member in your group. Doing so, will make it easier for you to notice changes in behavior or disposition in members. It should raise a red flag if a group member is more or less vocal than usual, or if a member has a consistent change in mood.

As a patient or caregiver yourself, you are aware of how rare diseases can impact an individual and how quickly a disease can progress. These changes can affect a person's behavior and interaction within the group. You may not be able to control these changes in a member, but you should be prepared to respond to them.

You may want to help explore the observed change during a group meeting or to talk privately with the member. The choice will be situational and dependent upon the person, the observed change, and your personal leadership and facilitation style.



Technique	Description/ Situation	Example/ Response
Focus the Group	Groups can get off task or members can distract the group from the topic at hand.	Don't dismiss the individual or the diverted topic. Instead, acknowledge and validate the other topic, but ask to come back to it and return to the original topic. For instance, say "(name) I am happy that you are sharing and I want to come back to this, but right now let's go back to ____."
Paraphrasing	This can be used to summarize what a member has just stated if they provided a lot of information all at once. It also ensures that you have the correct understanding of what was said by your group member.	An example of this would be to say, "(name), it sounds like you feel _____. Did I hear you correctly?"
Questions	Group member(s) are discussing a topic or experience that is confusing or you do not understand.	Ask questions. It shows you are listening and provides validation. Encourage other members to ask questions as well. Don't forget to ask open-ended questions to prompt a discussion, such as, "How does that make you feel?"
Silence	When there is silence within the group or unwillingness among members to talk.	Don't be afraid to let the group be silent. Some people may be gathering their thoughts. Silence is healthy. Don't feel the need to rush the process. Allow several minutes to pass then re-engage the group.
"I" Statement	Statements that begin with "I". This helps to provide validity and avoids feeling of being attacked.	Instead of saying "You handled that situation well," say "I feel that you handled that situation well."



*"Keep your face
always toward
the sunshine and
shadows will fall
behind you."*
- WALT WHITMAN

Resources: Facilitating and Leading Support Groups

Peer Support: Developing and Facilitating Self-Help Groups
<http://www.peerzone.info/sites/default/files/resources/U%20Penn%20Start%20a%20self%20help%20group.pdf>
Community Integration Tools is a resource created by UPenn. This specific resource guides individuals in the development and facilitation of support and self-help groups.

Start a Support Group
<http://www.adaa.org/finding-help/getting-support/support-groups/start-support-group>
The Anxiety and Depression Association of American provides general information that can be used with a variety of population types that discusses what you will need to begin a group as well as how to run a group meeting.


Techniques for Leading Group Discussions
<http://ctb.ku.edu/en/table-of-contents/leadership/group-facilitation/main>
Community tool box is a health resource. They provide several chapters on support groups, including this chapter series which discusses how to have and lead effective groups.

How to Lead Online

The basic foundations of group facilitation are the same but the online platform requires different techniques for set-up, communication, and approaches. Initially, you should keep your group closed and private. You will need to inform members about the risk of sharing their personal information, even in a private and closed online group.

Admitting members can be tricky. You do not want to turn anyone away, but (if possible) do a thorough search of those seeking membership to determine if they have a legitimate reason for wanting to join the group.

In the description of the group, indicate the focus, goals, and rules that members are required to follow.

 Rules often listed on group websites include:

- Keep postings and interactions with other group members positive
- No ads or sales promotions
- No vulgarity or sexually explicit posts
- Avoid topics like religion and politics
- Be open-minded

Clearly stated rules can help to minimize confrontation between members. If there should be a conflict you can re-direct offenders back to the rules.

Down the Rabbit Hole

Like Alice's adventures in the rabbit hole, the wonderland of the Internet comes with challenges that don't exist with in-person groups. The challenges are not more difficult, but they are different; and therefore require different approaches.

One of the challenges of an online group is communication. In-person you can interpret body language, verbal tone, or non-verbal cues. Without this information you will have to trust what a member states in a post. You won't truly know if a member is having a good day or a bad day. If a member is too quiet or too vocal you will be limited in your ability to probe the problem. If a member is not posting, they may be ill or they may be too busy to engage with the group. ■



Surviving Stormy Seas: Conflicts and Resolutions

"The threat of a stormy sky or sea will not keep a sailor on the shore." Unknown

From politics to religion, conflicts between members and leaders are a part of daily life. Often time conflicts occur because of external triggers. Sudden or unexpected changes, like the loss of a job, can make a member lash out during a group meeting. This behavior is likely not personal toward you or other group members, but is a coping or defense mechanism for the person. It can be difficult for a facilitator to know how to respond when these types of conflicts occur.



Listed are key steps you can take in order to come to a resolution. Throughout this process, be sure to maintain respect and model appropriate behavior for your group.

1. Stay calm and assess the situation. Who is involved and why?
2. Determine if you should allow the conflict to resolve itself or if you should intervene. Always keep safety as your top priority.
3. Decide if the conflict should be worked out in the group or if it should be handled privately.

4. Resolve conflicts by acknowledging the emotions of the members involved and by getting mutual agreement on the cause of the conflict.
5. Bring the members to a resolution or compromise, and be sure closure has been reached.



Managing Online Conflict

Conflict will happen with online groups, because members may feel more comfortable with being outspoken or disagreeable online. They may post something inappropriate that offends other group members.

Left unmonitored, online groups can get out of control fast. In these situations you can hope the conflict will resolve itself while you binge watch the Game of Thrones marathon or you can intervene. But, if other members are blowing up your email about an online conflict you should respond ASAP! To respect everyone involved work privately with the affected members to resolve the conflict.

Be impartial and stay neutral. Use the ground rules to frame a resolution. If a member will not adhere to the rules you may need to disable the person's ability to interact with the group. By ensuring your group adheres to the rules and stays focused on its goals, you can keep conflict to a minimum. ■



It's Show Time!

First Meeting Preparation

Think back to how you felt on your first day of high school with a new teacher and new classmates. Well, your first support group meeting may feel a lot like that. The difference being, you will be the one addressing a room of freshly scrubbed faces eager to learn something new.

Use the first meeting to set the tone with your group members. Be prepared to discuss the purpose and goals of the group. This first meeting is where you begin building relationships, rapport and trust with one another.

For in-person support groups, think about the layout of your meeting space. Arrive early to arrange seating and to set-up refreshments. The space should be open and welcoming.

Before you start the meeting cover the housekeeping details of: parking, where the restrooms are, cell phone etiquette, etc. Also think about the logistics of your agenda for the day. If you are a hybrid group and the plan is to incorporate speakers, make sure the room is accommodating and considerate of the speaker.

After the members settle in discuss confidentiality. Assure members that the meetings are a safe place for them to share their rare disease issues openly. It's likely you will have new members each week, so you will need to determine when you want to present confidentiality agreements to newcomers. It can be unproductive to review it each meeting. One solution is to have a confidentiality form to sign with the sign-in sheet. Of course, always start the meeting with introductions.



At your first meeting be sure to have on hand:

- Sign-in Sheet
- Confidentiality Agreement
- Visitor Agreement (if you plan to have a visitor or speaker)
- Group Assessment (this can be done via an online survey as well; members' feedback will help you to better guide your support group)
- Additional resources- some groups have newsletters that highlight events and information relevant to their disease or the rare disease community.

You can make your own materials, but also view the template materials included at the end of this section. ■

Templates and Resources

15 Rules of Engagement for Facebook Group Administrators
<http://socialmediaimpact.com/15-rules-engagement-facebook-group-administrators-facebook/#>. Social Media Impact provides examples of rules that can be applied to an online forum, community, or support group.

Procedures and Guidelines for Group Therapy
<http://www.apadivisions.org/division-49/publications/newsletter/group-psychologist/2011/04/group-procedures.aspx>
American Psychology Association provides examples on procedures and guidelines for in-person support groups. Support Group Feedback Form http://docs.nrcdv.org/pages/FVPSA_Outcome/DOWSupportgroup1.pdf. A sample of a group assessment or support group feedback form. This sample can be adjusted for both online and in-person as well specific for your group and function.

Support Group Facilitator Resources
http://www.alz.org/mnnd/in_my_community_13648.asp.
Alzheimer's Association provides many resources for support groups. Many of their resources can be adjusted to be specific for your community and forum. This resource provides additional links to samples and templates for items commonly needed for support groups such as sign-in sheets, confidentiality agreements, evaluations.

Survey Monkey
<https://www.surveymonkey.com/>
Survey Monkey is an online survey platform. Here you can create customized surveys for participants that pertain to your group and community. This can be sent online to participant's emails, creating more ease and flexibility in receiving feedback.



Standing Room Only

Marketing Maneuvers

To grow sales Charmin spends big money on all types of marketing to convince you that their bathroom tissue is best for your bottom. The point here is to say, even established brands like Charmin rely on marketing for growth and you should plan to do likewise.



As a group facilitator there are some key questions to ponder when planning a strategy of how to grow your support group such as:

1. How do people find your support group?
2. What makes your group unique?
3. What would encourage people to join?

Measuring Stick

You will want to know if your support group is effective. Conduct a survey to find out how members feel. As your group grows you will want to know if the group is meeting its goal or fulfilling its purpose to the members. This feedback can be solicited at every meeting, monthly or quarterly.

Supervision/ Advisors

You may want the assistance of a supervisor or advisor as the group grows. This person can be a physician, counselor, social worker, or nurse practitioner. You want an assistant who has experience with health and well-being. Members who are chronically ill or who are suffering from health issues, or emotional and psychological issues can manifest troubling behavior. It is important to have an assistant who knows the correct medical response to someone displaying suicidal ideation, chronic depression, or anxiety. ■



Marketing Interactive

List the things you were hoping to find when you searched for support and resources about your rare disease.

Now brainstorm a list of places that would make sense for this information to be available – online, physician's office (specialists, genetic counselors, primary care providers), foundations, etc.

Create a flyer or newsletter that can be distributed through these locations both online and print versions. Social media is one of your greatest (and primarily free) resources for marketing. You can utilize social media marketing to advertise your group and to let people know how to connect with you either in-person or online.

Check out the Global Genes toolkit How to Promote your Rare Disease Through Social Media (<https://globalgenes.org/toolkits/how-to-promote-your-rare-disease-story-through-social-media/introduction/>) for more info about the many ways to utilize some of the most popular social media platforms.

Resources: Online Support Groups

Online Support Groups: Nuts and Bolts, Benefits, Limitations and Future Directions
<http://www.counseling.org/resources/library/Selected%20Topics/Cybercounseling/Gary-Digest-2000-07.htm>
 This article by Juneau Gary and Linda Remolino discusses the in's and out's of starting an online support group and outlines the strengths and limitations a support group can offer a population.

Online Forums

Facebook
<https://www.facebook.com/>
 Facebook, a popular social media site. You can utilize the "groups" function to create a virtual support group. Facebook is a great platform for networking, marketing and connecting from your computer.

Skype
<https://www.skype.com/en/>
 Skype offers video and phone calling options. This can be used for group communication and meetings from your home. It can be accessed through computer, phone and tablet; Skype can also be used for free with limitation in function.

Google Hangouts
<https://hangouts.google.com/>
 Google Hangouts is a communication service that allows users to interact through text, voice, and video chat with a multitude of other users. Google Hangouts is accessible through your Gmail or google plus account and can be accessible on your phone, tablet and computer.

Inspire
<https://www.inspire.com/>
 Inspire is an online resource to create an online meeting community. Inspire acts as a moderator for these different online groups, ensuring group rules are followed and maintained.

Welcome to Something Bigger!

*"It's not in the stars
to hold our destiny,
but in ourselves."*

- WILLIAM SHAKESPEARE

You and your group are a part of something bigger—THE RARE COMMUNITY! Building connections within your specific disease community is absolutely the most vital part of your efforts. Members will tell you that the depth of the connection they feel with others in their rare disease community is hard to describe. There is an innate sense of closeness and empathy that comes with a common diagnosis.

Like we said in the beginning you are not alone. You and the members of your group are part of an estimated 30 million Americans and 350 million people worldwide that are affected by a rare disease. While the diseases and the symptoms may be different, people in the rare community often share the same challenges and fight for the same changes. This is a powerful thing! As the leader of your group it is your responsibility to make sure your members understand this connection and to provide them access to additional support in these areas. Rare is everywhere and is frankly not-so-rare.

Caroline's Story

My son is still undiagnosed and sometimes that lack of diagnosis can create the most feelings of isolation. With no diagnosis, there is no group or community whatsoever to belong to. There are obstacles, which are persistently challenging for those without a diagnosis. And though each case is unique, we all share common threads. I could not bear thinking that there are other families struggling alone out there. So I started an undiagnosed support group for families in San Diego. When we first started, it was in a causal setting. A few of us sharing information, seeing if anything overlapped with one another, giving each other new and different approaches to finding a diagnosis for our children. But now, meetings are more structured; we meet four times a year at a location that volunteers their space to us. We bring speakers to present about topics and resources relevant to parents of undiagnosed children. Right now our focus is on growing the group here in San Diego with a goal of supporting the local undiagnosed community along their journey to diagnosis.

-Caroline Cheung-Yiu, Parent Advocate

Contributors

Content for this Toolkit is Proudly Provided by:

Global Genes Would Like to Thank This Toolkit's Contributors and Participants:

Anne Leserman, LCSW

Assistant Director of Community Services
Huntington's Disease Society of America

Melanie Wong, Executive Director

National Adrenal Diseases Foundation

Mary Jo Strobel, Executive Director

American Partnership for Eosinophilic Disorders (APED)

Stacey Barton, MSW, LCSW

Clinical Social Worker

HDSA Center of Excellence at Washington University School of Medicine

Cheryl Sullivan Staveley, RN

Parent and Caregiver Advocate, Support Group Leader
Huntington's Disease Society of America

Lauren Stiles, President and Co-Founder

Dysautonomia International

Marc Yale, Senior Peer Health Coach

International Pemphigus & Pemphigoid Foundation

Tiffany Early, Patient Advocate

Blogger at Crazy, Chronic Life (www.crazychroniclife.wordpress.com)

Lisa Palmer Auerbach, Patient Advocate

Caroline Cheung-Yiu, Parent Advocate

San Diego Undiagnosed Family Support Group



Let's Stay Connected!

Global Genes is invested in collecting and then sharing best practices and lessons learned as well as devoted to celebrating successes of the rare disease community.

Submit questions, feedback and your action steps here:
www.globalgenes.org/toolkitfeedback

Follow us @globalgenes

If you are interested in contributing to a future toolkit topic, please email:
advocacy@globalgenes.org.

You can view upcoming toolkit topics and access past titles here:
www.globalgenes.org/toolkits

If you would like to donate to Global Genes' toolkit program, please do so here:
www.globalgenes.org/donate

