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Authors

Geisler, Amaris
O'Connell, Katie A
Pandya, Rachita
[et al.](#)

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Importance of and instruction for starting a vitiligo patient support group

Amaris Geisler^{1*} MD, Katie A O'Connell^{2*} MS, Rachita Pandya³ BA, Amanda Milburn⁴ BS, Camille Robinson⁵ BS, Angela Parks-Miller⁶ CCRP CWCA, Patrick M Dockins⁷ MS CAE, Richard H Huggins⁶ MD

*Authors contributed equally

Affiliations: ¹The City College of New York School of Medicine, New York, New York, USA, ²Eastern Virginia Medical School, Norfolk, Virginia, USA, ³California University of Science and Medicine, Colton, California, USA, ⁴New York Institute of Technology College of Osteopathic Medicine, Old Westbury, New York, USA, ⁵Duke University School of Medicine, Durham, North Carolina, USA, ⁶Henry Ford Hospital, Department of Dermatology, Detroit, Michigan, USA, ⁷Global Vitiligo Foundation, Chicago, Illinois, USA

Corresponding Author: Richard H Huggins MD, Department of Dermatology, Henry Ford Medical Center–New Center One, 3031 West Grand Boulevard, Suite 800, Detroit, Michigan 48202, Tel: 800-436-7936, Email: rhuggin1@hfhs.org

Abstract

Starting and maintaining a vitiligo support group can appear to be a daunting task. However, with proper planning and organization, the process can become manageable and rewarding. Our guide details the reasons to start a vitiligo support group, how to start a group, how to run a group, and how to promote a group. Legal protections and details regarding retention and funding are also discussed. The authors have extensive experience leading and/or assisting support groups for vitiligo and other disease states and we also sought out other current vitiligo support leaders for their valuable insights. Previous research has found that support groups for various medical conditions may have a protective effect and membership can build resilience among participants as well as foster a sense of hope regarding their disease. Further, groups can provide a network for those living with vitiligo to connect with, uplift, and learn from one another. These groups provide the opportunity to initiate lifelong connections with those facing similar circumstances and provide members with new insight and coping strategies. Members can share perspectives with one another and empower one another. We encourage dermatologists to provide vitiligo patients with support group information and to consider being involved in, starting, or otherwise supporting them.

Keywords: guidelines, patient support, vitiligo

Introduction

Why start a vitiligo support group

Vitiligo is a relatively common condition; approximately 1 in every 100 individuals in the United States has vitiligo, and a third of them are children [1,2]. Vitiligo equally affects both males and females and has not been demonstrated to have any racial, ethnic, or socio-economic predilections [3]. The condition can have a profound impact not only on patients' quality of life, but also on that of their caregivers [1,4]. More significant dermatology-specific quality of life impact has been reported in women, patients with dark skin (type IV-VI), and in patients with vitiligo on parts of the body which are visible or associated with sexuality [5-9].

Prior research has suggested that vitiligo support groups may have a protective effect for patients with more severe disease [10]. This supports evidence regarding support group use in other conditions such as hidradenitis suppurativa (HS), [11]. A recent study of a tinnitus support group revealed that group membership-built resilience among participants and instilled a sense of hope regarding their disease [12]. This is especially important considering, in HS, it has been shown that patients with higher resilience levels experience smaller decreases in quality of life as depressive symptoms increase.

Caregivers of patients with vitiligo may experience disease-related distress whether or not their child is significantly concerned about their condition. Support groups offer opportunities for the families of those living with vitiligo to interact. One study found that parents of children with vitiligo have significantly more psychological problems and poorer quality of life compared to parents of unaffected children [4]. Furthermore, in this same study, an increase in body surface area of vitiligo in children was correlated with a decrease in parental quality of life [4]. As such, researchers recommended support group referral to alleviate the burden on caregivers. Support groups may also serve as the first meeting place for children with this condition to connect and even offer mentorship as older children can serve as role models to younger children, sharing their experiences and coping strategies.

Some support groups have a physician who regularly attends meetings and/or serves as a resource for members. Physicians are an invaluable source of education for members; often they can address and correct common patient myths [13]. For example, particularly at the beginning of the coronavirus pandemic, many patients with vitiligo were worried if they were at increased risk for contracting COVID-19. Given our strong vitiligo national support group network, we were able to reach out to all the groups and rapidly disseminate reliable information to ease undue distress amongst our members.

Physician involvement in support groups may be beneficial not only for support group members but also physicians themselves. These venues offer an opportunity for more extended discussion in comparison to a traditional ten-to-fifteen-minute clinical encounter. In this setting, there is an opportunity to gain valuable insight into how a patient's disease impacts their daily lives and into the nuances of living with vitiligo. Additionally, patients can provide feedback on treatment and suggestions for improvements [14].

Finally, support groups have the potential to foster the momentum to bring a number of different voices to the table including individuals living with vitiligo, the medical community, industry, and other stakeholders. This allows for the formation of

partnerships within which support group members can provide the voice of the patient, advocate for the disease, and inform future research to improve quality of life and treatment.

Although no prospective studies have been done to evaluate the effect of support group participation on quality of life in vitiligo, in our experience patients welcome the opportunity to connect. Many members develop a greater degree of acceptance and at times are even enabled to embrace their condition during their time with vitiligo support groups. We strongly encourage dermatologists and other medical professionals who see vitiligo patients to provide their patients with support group information.

Discussion

How to start a vitiligo support group

Starting a vitiligo support group can appear to be a daunting task. However, with proper planning and organization the process can become less cumbersome and can be quite rewarding. One of the initial action items to complete before starting a support group is to conduct thorough research. This research may help you decide whether you want to join an established support group, affiliate with a medical entity (i.e., local physician office, hospital, university), or create a new, standalone support group. If choosing to join an established group or affiliate with a medical entity, consider requesting an affiliate agreement or contract and reviewing this with legal counsel, if possible. In Appendix 1, we provide a detailed framework of other items to consider with regard to the support group development process. Specifically, we include considerations for the initial meeting among founders followed by meetings two and three. Of note, there are many resources and support groups that have previously been developed which can provide ideas, advice, and general information to guide you in achieving the mission of your specific support group. You should customize the implementation of all of these recommendations to your specific needs and resources [15].

Once you have conducted your research to build the framework for your support group, one of the first

goals may be to create a name and define the goals of your group. Writing a mission statement is critical and can outline why your group exists, what you want to accomplish, and how you want to direct the group to reach your set goals. After solidifying your mission statement and goals, you may want to consider identifying the structure of your support group. Your group can be peer-led, professionally-led, or a combination of the two [16]. You may also want to establish whether your group will be in a discussion or lecture format, or a combination of the two [17]. The structure of your group will help determine whether you want to collect a fee for members to attend meetings and how often meetings will be held (e.g., once a month). An important factor that will need to be considered is the venue for your meetings (i.e., hospital or library conference room), [16].

The creation of a support group requires the founder(s) to elicit interest and identify prospective participants. Support groups thrive because of their participants, so it is important to identify patients who are looking to be a part of a vitiligo support group and would benefit from being a part of this experience [18]. Partnering with dermatologists in your area can be beneficial, as they can identify patients who might be interested [18]. In the age of social media, Facebook and Twitter are tools that you can use to gauge interest and that can also provide a way for future participants to connect and stay informed of your group's happenings [15].

Lastly, it is a good idea to consider the expectations for your support group. This would include attendance policies, confidentiality agreements, minimum activity level required of each participant, announcement distribution, protection of minors, and ground rules (resources for much of this is discussed in [Appendix 1](#)).

Legal protections

An often-overlooked part of developing a support group is determining how to best protect the founding members (incorporators) and board of directors from liability. Herein, we describe three ways to do so. The first is through incorporation. Incorporation laws vary from state to state so it is best to visit your Secretary of State's website (or

equivalent) for the options available to you. In some cases, your state may offer a Not for Profit (NFP) Corporation status or something very similar. Many states will have documentation online or a printable guide on how to establish a corporation within that state. In [Appendix 2](#), we provide a detailed framework of items to consider with regard to creating a non-profit support group. It's worth noting that you should not need to hire an attorney or company to complete the necessary paperwork. If you find you need additional help you can reach out to the state office responsible for incorporating businesses or a local office of the Small Business Administration (SBA).

Although each state is different, they generally have common requirements when it comes to creating a corporation. These include a unique name, a registered agent who resides in the state of incorporation (this person will act as the contact to receive all official state mailings and communications), Articles of Incorporation, and an application fee. Articles of Incorporation state the purpose of the organization, the name(s) of those forming the corporation (incorporator(s)), and potentially, the officers and board of directors responsible for the organization.

The second way to help protect the organization is through general liability insurance and directors and officers (D&O) insurance. The former provides monetary protection for general legal claims while the D&O insurance provides specific coverage for the actions and decisions of the directors and officers of the organization. For a lengthier description of what D&O insurance often covers visit the Insurance Information Institute at iii.org.

Lastly, it is important to develop bylaws and operational policies and procedures. Although the Articles of Incorporation answer the question about what an organization will do, the bylaws, policies, and procedures answer the how. Having policies and procedures in place act to channel authority while also providing necessary checks and balances. These provide organizations with a road map on how to run the organization year after year.

How to run a vitiligo support group

As mentioned, support groups may take place in either a discussion, lecture, or hybrid format [18,19].

Box 1. Icebreaker questions.

Tell us something unique (i.e., a special talent, interesting hobby, or fun fact) about yourself.

What is your favorite book and why?

If you could invite anyone (living or passed) over for dinner, who would it be and why?

What is the best piece of advice you have ever received?

What is something you wish you had known when you were first diagnosed with vitiligo?

What is something positive about yourself that you have learnt through living with vitiligo?

Group discussions are valuable for giving attendees the opportunity to share their stories and receive input from group members in an informal environment [18,19]. Lectures are valuable for learning from field experts and having the opportunity to ask questions [18,19]. Other ways to incorporate education into the meeting would be discussing books or personal memoirs related to vitiligo [18,19].

Generally, a group leader may want to consider arriving early to the meeting to distribute food and handouts, as well as greet members [18,19]. New members can be introduced to a “buddy” to help

them integrate into the group and having all members wear nametags can be helpful [18,19]. Consider preparing icebreaker questions to have on hand (**Box 1**). Many group leaders choose to sit facing the door to greet latecomers and direct them towards an open seat [19]. At the onset of the meeting, the leader should consider establishing ground rules (e.g., strict confidentiality, avoidance of side conversations), [19]. It is suggested group leaders make an effort to start and end meetings on time as members may have other responsibilities, and time should be built into the end of the meeting for attendees to linger, socialize, and ask the lecturer/leader questions [19].

As a group leader, one may want to consider preparing to ethically handle the following member types: 1) *Monopolizer*—attendees who talk too much can be redirected (e.g., can anyone else relate?); 2) *Silent attendee*—may be gently included but be careful not to push if uncomfortable; 3) *Angry attendee*—ask others in the group to comment or relate as this indirect advice may be more palatable; 4) *Disagreeing attendees*—allow but ask to re-state in a friendly way if coming across as abrasive; 5)

Box 2. Tips from established support group leaders.

“Wristbands with your marketing tag and contact information is a fun way to spread awareness without handing out flyers which can be a waste of money/time because most people throw these away. However, they love collecting and wearing wristbands.”

“Maintaining a support group requires a heavy reliance on social media. Setting up a google account for email communication and Google Drive organization has been helpful.”

“I wish I would have understood the importance of addressing and having a mental health provider connected to the group to talk about “mental health wellness.” The physical aspect is important to address but mental wellness is critical.”

“There are many different goals you can establish for the group- purely supportive, doctor/patient relations, advocacy and education (health fairs, school visits, college presentations), etc.”

“Leaders should understand that attendee participation will vary from one meeting to the next. As a leader, it’s important to realize in most cases it’s nothing you’ve done wrong. Your role is to support those who attend.”

“Never cancel a meeting simply based on prior attendance. As a leader, you must be willing to give the same zeal if you have 1 attendee or 100. The very meeting you consider canceling could be the one where a new member attends that really needs the support.”

“Recognize everyone is at a different place in their journey of living with vitiligo. Some may be comfortable talking about their vitiligo while others may not be, regardless of age.”

“Language is important. Acknowledge that some people are not comfortable referring to vitiligo as a disease. The language of support groups will be what attracts or sways people away from joining.”

“Don’t try to do everything yourself because it can cause burnout. Ask group members if they’re interested in taking on leadership roles to assist you.”

“Consider partnering with other support groups to build a stronger, more united community. Can also partner with dermatologists for support.”

“Register name of group with state to make sure that name is not already taken; establish non-profit/LLC or Incorporation/Tax ID number status with the state (Division of Corporations would be a good starting point); file for Tax Exemption status with IRS to receive funding from companies.”

Challenger—if someone challenges your authority, do not get defensive. Alternatively, you can ask them to elaborate and own up to any legitimate points; 6) *In-crisis attendees*—provide attendees who need extra help with recommendations for additional services or professionals but be careful to not endorse any sort of direct relationship with the group or guaranteed effectiveness [19].

How to promote a vitiligo support group

Building the group's reputation and generating a large, loyal following, especially at onset, *will* take time. Networking and connections are essential; having a well-known entity support your mission will often be the best way of promoting the group (think: multiplying effect), [19]. **Box 2** provides some suggestions for free advertising to help spread awareness about the new-found group [19].

Retention and funding

Starting a vitiligo support group, much like any advocacy group, undoubtedly comes with its associated financial expenses (**Box 3**). These can include funds needed for refreshments, venue space, or promotional activities [20]. For groups just beginning their journey, more immediate sources of funding could be best met, initially, through donated support or fundraisers [20]. Meetings can be conducted at a local community center, library, or other public space [20]. Additionally, these centers may be willing to offer access to their computer and printing services, which would be helpful in creating flyers [20]. A very common meeting expense is food. Serving refreshments at a meeting can be beneficial,

especially if the meeting overlaps with a typical mealtime, and can be used as an enticement to get individuals to attend. Several group members may also be willing to prepare and bring refreshments to the meetings [20]. Of course, the snacks and drinks can be omitted if it is impractical in the context of finances and/or social dynamics of the group. [19].

As the support group continues to expand, so will its financial needs. Alternative funding sources may need to be considered to augment the budget. Here, it becomes vital to understand the unique needs of the support group itself and the wider community within which it exists before securing external funding from local businesses or organizations. For example, if the group is considering renting a more permanent location for meetings or looking to sponsor group activities, hosting fundraisers could be an effective way to raise this money [20]. The simplest way could be to obtain financial contributions from participating group members, but, if undertaken, this should be done in a meticulous and transparent manner [19]. If the group is also interested in raising community awareness or creating a bonding experience, hosting a community event like a car wash or talent show may also be an option [20].

When deciding which industry partners with which to collaborate, it is important to prevent misrepresentation of the support group and preserve its integrity within the community. This can be achieved by instituting a conflict-of-interest policy. Additionally, obtaining state and national

Box 3. Suggestions for free advertising.

- Find an anchoring organization (e.g., state and/or national organization) and advertise on their website/social media [15].
- Affiliate the group with an educational or healthcare institution who will include support group information in their other promotional activities. Be sure to find out how often you need to renew your listing [15].
- Generate an email list of professionals in the area who work with Vitiligo patients so they can post flyers or bring up your group's information in discussion [15,18].
- Advertise in local newspapers, which often contain free listings of support groups [15]. Beware of publication deadlines.
- Keep an eye out for community bulletin boards where you can post information about your group (e.g., grocery store, library, pharmacy, government buildings, etc.). Keep a few flyers in your car at all times, so you will always be prepared [15].
- Given our increased dependence on technology, have an easy to remember social media handle/Facebook group name/website that you can refer the prospective group member to.
- If hosting a lecture meeting, use the speaker to your promotional advantage. This will not only promote the particular meeting they are speaking at but will also greatly increase exposure of the group's mission to the speakers' network [15].
- Word of mouth is known to be the most effective. Encourage attendees to share personal anecdotes with others about their experience; [15,18] people are most likely to take advice from someone who has already directly participated.

nonprofit status or becoming affiliated with a group who already has should be considered, as these can greatly enhance the fundraising potential of a support group. This process is discussed in Appendix 2.

No matter the avenue, garnering funding for support groups requires planning and a joint effort, which is heavily dependent on group retention. Particularly with vitiligo, where self-esteem may be affected due to the visual nature of the disease, ongoing support is vital for rebuilding confidence [13]. Holding meetings on a consistent schedule (e.g., the second Thursday of every month) can create a sense of consistency that may help support member retention. Importantly, refraining from cancelling meetings regardless of the turnout may also help support longevity. To maintain participation, it is also important that every group member receives prior notifications regarding meetings or events and reminder Emails or messages may also be helpful. Furthermore, sending special occasion cards (birthdays, anniversaries) signed by group members could help foster a sense of inclusion [21]. Above all, it is vital that the group collectively creates a safe and respectful environment, where each member feels valued [19].

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Conclusion

Vitiligo is a relatively common skin condition. The condition may significantly impact the well-being of both patients and caregivers. Previous research has identified the importance of support groups in other conditions as an avenue to reduce perceived burden of disease. Running a support group may appear to be an overwhelming task. We have attempted to help alleviate some of these concerns by making use of the extensive support group experience of the authors along with additional feedback from support group leaders affiliated with the Global Vitiligo Foundation in the composition of this manuscript. Although, we acknowledge that the starting and maintenance of any specific vitiligo support group will require individualized decisions based on the preferences and resources of the particular organizer and their membership, we have sought to provide an overall framework.

Potential conflicts of interest

RHH is a primary investigator for Incyte, and a sub-investigator for Pfizer and Immune Tolerance Network. AG, KO, RP, AM, CR, AM, PD have no relevant conflicts of interest to disclose.

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SUPPORT GROUP DEVELOPMENT PROCESS

You have decided to start a support group! Congratulations! We know this can be both an exciting time and a scary one. Please use this document as a guideline to help you fulfill your goals. There is more than one path to establishing a support group and we hope this document helps you successfully start down your path.

Meeting #1 - Founders

AGENDA

Topic(s): Ideation and next steps

1. What is it that we want to do?
2. Who do we want to do it for?
3. How do we want to do it?
4. What would the future look like after we have done it?
5. Group name
6. What additional resources do we want to have in place from the start?
7. What committees will be needed to help spread the work?

IDEAS AND THINGS TO CONSIDER

Ideas for question 5

- Include the name of the disease in your group's name.
- Search your Sec. of State's name database to make sure you are not duplicating a name.
- If set on a name, consider developing social media accounts
- Developing a Facebook page to act as the group's interim website

Ideas for question 6

- A designated email for the group
- A shared online digital storage account

Ideas for question 7

- Education and meeting planning - Develop topics and ideas for meeting content
- Governance - Bylaws and policies and procedures
- Communications - social media, website, emails
- Recruitment and Retention - outreach to potential attendees and follow up with those who miss meetings

RESOURCES

The items listed below are not an exhaustive list but are designed to give you ideas and opportunities.

Free email accounts

- Gmail
- Outlook
- Yahoo

Free digital storage

- Google Drive
- Dropbox
- One Drive

Where to recruit your guiding committee

- Your doctor's office
- MyHealthTeams.com
- Facebook

Agenda writing

- hbr.org/2015/03/how-to-design-an-agenda-for-an-effective-meeting
- boardable.com/blog/board-meeting-agendas/

Potential Meeting Locations

- Public Library
- Where you work
- Local Hospital
- Religious facility (church, synagogue, mosque)
- A local non-profit

Brainstorming

- Internet Search – brainstorming techniques

NEXT STEPS

- Recruit a guiding committee - Ideally 3-4 or more people with the condition or their caregivers
- Draft the agenda for the next meeting - Be upfront about the time commitment and send it with the invitation
- Determine where to host the next meeting

Meeting #2 - Founders + small group

AGENDA

Topic(s): Group ideation and next steps

1. Set the ground rules for communication and confidentiality
2. Brainstorming the "what", "who", "how" and what the future would look like after the work
3. Gather contact information, if needed
4. Share highlights of the next meeting
5. Debrief
6. Ask them to bring a +1 to the next meeting

IDEAS AND THINGS TO CONSIDER

Ideas for agenda topic #2

- Agenda item #2 will generate the foundation for developing your mission and vision (agenda #5).
 - At this point, don't tell the group they are actually helping you draft the mission and vision. For some people, this can be overwhelming.
- Add in the founder's ideas: two options
 - Share the founder's initial thoughts and ideas from meeting number one. Encourage the group to add on, adjust, or start over
- OR
- Don't share your ideas right away. Let the energy of the group carry the direction it goes. Incorporate your ideas along the way or wait until later in the discussion to incorporate them with the group's ideas.
- Use sticky notes and the walls of the room
 - Put the "who" on one wall, the "what" on another, etc.
- Use large sticky easel pads
 - Station them around the room with "who" on one, "what" on another, etc.
- Use a large chalk or white board, if in the room.

Ideas for agenda item #7

- Empower each person in the small group to invite at least one other person with the condition or a caregiver to the next meeting
- Asking people to recruit people can make them feel nervous. Asking them to bring a +1 to the next meeting is doable and feels less intimidating

RESOURCES

The items listed below are not an exhaustive list but are designed to give you ideas and opportunities.

Meeting ground rules and confidentiality

- hbr.org/2016/06/8-ground-rules-for-great-meetings
- extension.umn.edu/public-engagement-strategies/setting-ground-rules-productive-discussions
- slideteam.net/meeting-rules-defining-dos-and-donts-discussions-management.html
- blog.lucidmeetings.com/blog/using-ground-rules-improve-engagement-excellent-team-meetings

Brainstorming

- Internet Search – brainstorming techniques

Online meeting evaluation

- blog.hubspot.com/service/free-survey-maker-software

NEXT STEPS

- Create a handout for the next meeting - Contact info. for the leader(s), Facebook page (if built), and the draft mission and vision statement
- Determine where to host the next meeting
- Email group a brief summary of the meeting within 24-48 hours - Bullet points. Share the next meeting date and location
- Put together an online meeting evaluation for the next meeting
- Think about the committee goals, strategies, and time commitments.
See the next meeting for resources to help you draft committee charters

Appendix 1

Meeting #3 - Founders + small group + 1+

RESOURCES

The items listed below are not an exhaustive list but are designed to give you ideas and opportunities.

Committee charter examples

- globalvitaligofoundation.org/committees/
- resources.uwcc.wisc.edu/Governance/Board%20Committee%20Charter%20Template.pdf
- policy.usc.edu/resources/governance-charters/committee-charter-template/

Online meeting evaluation

- blog.hubspot.com/service/free-survey-maker-software
 - A good number of them should have a event feedback template that you can use

Mission and vision

- donorbox.org/nonprofit-blog/nonprofit-mission-statement
- topnonprofits.com/mission-statements/
- boardbuild.org/how-to-craft-a-vision-statement-that-will-guide-your-nonprofit/

AGENDA

Topic(s):

1. Two options:
 - a. Medical or Mental Health provider talks about an aspect of the disease, the mental health ramifications of the disease, or a general Q&A.OR
 - a. Take an idea from the brainstorming session and make it happen.
1. Share the summary of the brainstorming exercise from the last meeting.
2. Share the ideas for potential committees/taskforces
3. Recruit individuals to form a small committee that will tackle the task of drafting a mission and vision statement based on the brainstorming discussions

IDEAS AND THINGS TO CONSIDER

Ideas for agenda topic #1

- Prep the presenter...
 - to be practical, not theoretical
 - to have a shortlist of practical takeaways
 - to understand the group size and your mission and vision
- Whatever the activity make sure people walk away with practical takeaways.

Ideas for agenda topics #2&3

Committee/Taskforce charters should contain

- How the committee relates directly to the brainstorming and eventually the mission/vision/strategic plan
- Composition of the committee
 - How many and what kind of people (people with the condition, doctors, parents, children, etc.)
- Time commitment
 - General - 1 month, 6 months, 1 year, etc.
 - Specific - Estimated number of meetings or conference calls
 - Work to be completed outside the meetings
- General description summary of what the group will do
- Duties and responsibilities
- Deliverables

NEXT STEPS

- Email group a brief summary of the meeting within 24-48 hours - Bullet points. Share the next meeting date and location
- Work with the small group to develop the mission and vision
- Review meeting notes and brainstorming exercises. Pull ideas from them to develop future meeting content
- Consider developing a draft of the group's bylaws. *Initial focus on officers and committees. Consider terms and how appointed.*
- Put together an online meeting evaluation for the next meeting
- Look into acquiring 501c3 status.
- See Appendix 2 for information on how to do this.*

Appendix 2

Your journey to start a non-profit support group [501(c)(3)]

If you have not already completed, consider following the Support Group Development Process meetings 1-3.
(See Appendix 1).

Review state specific requirements for starting a non-profit legal entity.

[Consider reaching out to your local Small Business Administration (SBA) for assistance.]

Most states will require the following:

1. Articles of Incorporation
2. Bylaws
3. List of Directors and/or officers
4. File paperwork and pay fee

Receive state approval of your non-profit entity

Obtain an Employer Identification Number (EIN)

1. IRS Form SS-4

Receive IRS tax exempt letter

Federal Tax Exempt Status

1. File federal [Form 1023-EZ](#) within 27 months of forming the non-profit
2. Pay fee

State Tax Exempt Status

Search your state's Secretary of State website for the application.

Hold board meeting

Draft and/or accept:

1. Bylaws
2. Whistleblower policy
3. Document retention policy
4. Insurance policy expenditure

**New 501(c)(3),
pending federal
approval**