



**VITILIGO SUPPORT INTERNATIONAL**  
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*Fall Edition Newsletter 2017*

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## *Starting a Local Support Group*

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There is nothing like the opportunity of meeting other people living with vitiligo and the chance to share support and experiences in person. Even those in a very supportive family or environment describe feelings of sadness, confusion, and isolation. They just want to meet and talk with others who've been where they are and understand.

Because there are so few established vitiligo support groups, VSI frequently receives requests for information on how to start a group. To further complicate matters, many people who contact VSI have been unable to find a local dermatologist who is particularly supportive of vitiligo treatments, which can be limiting with regard to support group assistance. However, with or without medical support, you can still have a successful support group!

While VSI does not currently have the capacity to oversee local support groups, we are happy to share the following information and guidelines for those who are interested in starting a local group.

## ***Am I Qualified to Start a Support Group?***

Initially, many people worry that they are unqualified to start a support group. The good news is that peer-to-peer support is just that. These groups are not about cures or medical procedures. They are about the kind of emotional support that comes from sharing feelings and experiences with others who know first-hand what you're going through. If you are compassionate, organized, responsible, and have time in your schedule to invest in a project, this may be just for you!

The format you choose for your local support group will depend somewhat on personal preference and availability of local resources.

### ***Format Considerations:***

- Age of attendees - children, teens, adults, or multi-age
- Intended purpose: Social friend-to-friend support, educational with speakers, or a combination
- Local resources – availability of local physicians or speakers knowledgeable about vitiligo and current treatments who are willing to participate

### ***Social vs. Educational:***

If your primary interest is connecting with others and sharing experiences, then a social group might work well for you.

If you are fortunate enough to have a local dermatologist experienced with current vitiligo treatments who is willing to assist in the effort and participate in meetings, even if on an occasional basis, this is a good foundation for an educational-based group, or a social group with occasional educational meetings.

### ***Where to Meet:***

No matter which format you choose, for everyone's safety, until well-established, meetings should ALWAYS be held in public venues. As much as you would like to be able to trust that everyone who might respond has the same interests as you, in this day and age that can't be taken for granted.



Most cities have public meeting rooms that can be reserved in advance for free, or at very low cost, such as:

Hospitals      Churches  
Schools      Malls  
Libraries

The age of the attendees can also affect the type of venue you select. Parents of young children with vitiligo might consider meeting in a local fast food restaurant with an indoor playground. A teen group might prefer a coffee house, or the food court in a local mall. Adults might be interested in meeting at a restaurant for a happy hour, or brunch.

### ***Meeting Agenda:***

#### **Sign In:**

Be sure to have a sign in sheet ready where attendees can sign their name and email address to be contacted for future meetings. Be sure you can read each entry so that you will be able to add new attendees to your notification list.

You could also list a few simple tasks that others might volunteer to help with at a future meeting, such as program ideas, providing refreshments, distributing meeting flyers etc. Don't be afraid to ask others to help! Assigning small duties encourages feelings of belonging and inclusion in the group.

#### **Keep it Simple:**

For your first few meetings don't worry too much about organizing a program. Most people appreciate the opportunity to share stories and become acquainted. You can begin with something simple such as going around the room and asking each person to share their name, how long they've had vitiligo, and what they hope to get from the meeting. While a simple exercise like this can serve as an ice breaker, it also opens the door for discussion, helping to build camaraderie and feelings of acceptance. This unstructured type of interaction can be very beneficial. Not only does it give participants the opportunity to express their feelings, but learning more about the backgrounds, skills, and interests of your attendees can lead to ideas for future meetings.

#### **Refreshments:**



Refreshments are certainly not required, but always enjoyed. You could offer a simple snack like chips or cookies, and a beverage. You may have members who work in food service who could provide some type of snack for future meetings. Depending on the time of the meeting, you could ask if others might be interested in chipping in to have pizza and soft drinks at the next meeting. If there is interest, you could include the information on the upcoming meeting email and flyer.

### ***How Often Should you Meet?***

*Don't make promises you can't keep!* For the first year or so, it's best only to plan one meeting at a time. As tempting as it is when you are filled with the energy of the initial meeting, it is never a good idea to announce in advance that you will be meeting regularly, such as once a month, or every other month, etc. No matter how well intended you are, conflicts can crop up. Once you've announced meeting dates, there are expectations. People will begin making plans and arranging their schedules accordingly.



Until the group is large enough with enough committed leaders to conduct a meeting in the absence of the designated leader, it is best not to plan too far into the future.

If you have a general idea for the next meeting date, this would be something to discuss with others to try to find a time most convenient for the majority. However, it's certainly not imperative that you select your next meeting date right then. The discussion will give you an idea of times and dates that do, or don't work for the group. You can always follow-up by email once you've had time to work out the details.



### ***Getting the Word Out:***

Once you have decided on the format, and arranged for a meeting space, you will need to make meeting flyers. These could be created and printed from a computer, or handwritten on a sheet of paper. They don't need to be fancy, just big enough to include all of the relevant information, and be seen from a distance.

### ***Meeting Announcements Should Include:***

- **Date, time, location**
- **Format/Agenda:** brief explanation of what your meeting will accomplish, such as social time to discuss how vitiligo has affected your life, or, a program of speakers and topics etc.
- **Contact:** for personal security, announcements should use first names only, and never include personal contact information such as a phone number or mailing address. It is recommended that you set up a new email address dedicated specifically to this group. When selecting the new email address, it's a good idea to use something relevant, but again, no personal information. Something like [your city-vitiligosupport@xxx.xxx](mailto:your-city-vitiligosupport@xxx.xxx) is safe and easy to remember.
- **Future Meetings:** You should include a note on each announcement instructing those who are interested but unable to attend this meeting, to respond requesting to be placed on the email notification list for future meetings.
- **Spam Disclaimer:** in this day and age many people are wary of sharing their email address for fear of receiving spam and solicitations. It might be a good idea to include a small note that email addresses will only receive occasional meeting notices and updates and will not be shared or traded.

***For a Sample Meeting Flyer: [Click Here.](#)***

### ***Where to Place Announcements:***



Many public areas such as libraries, grocery stores, post offices, colleges, or restaurants have public bulletin boards for posting flyers and announcements. Some dermatology offices permit leaving flyers in their waiting rooms (just be sure to ask for permission!) Some newspapers have sections for posting free meeting notices. Some television and radio stations have a weekly time when they will announce public meetings. If you have any students involved, you could ask if their school would include the information in their daily announcements, and mention (if the school permits) that information sheets can be picked up in the office, then drop off a few at the office.

For future reference it's a good idea to keep a list of the places where you placed announcements. As your group grows and others are helping, you can divide the list of locations and be sure you're not duplicating. You should also note any places that you may have asked permission, but did not permit the notice.

### ***Information and Liability:***



You should be prepared to receive all types of communication including requests for medical advice or assistance. Unless you are a licensed professional or physician, you *should never* attempt to answer medical questions, provide medical advice, or offer any type of medical recommendations or suggestions. While it is unlikely that you would be held legally responsible for providing incorrect advice, we live in a very litigious society.

It's OK to discuss your personal feelings and experiences, but making medical recommendations based on your personal opinion or experience can cause problems. Remember that *your experience* with vitiligo is just that - *your experience*. There are a great many factors that make each person's vitiligo experience unique to themselves. This not only includes the circumstances of when a person developed vitiligo, where it is located, or how it spread, but each person's experience with treatment varies as well. Just like the types of vitiligo, there are a great many factors involved with each person's response to a particular treatment.

If you are facilitating a social, peer-to-peer support group and do not have a licensed professional to assist with medical questions, you have a couple of options:

- You can direct the individual to VSI's website at [www.vitiligosupport.org](http://www.vitiligosupport.org). The home page contains a lot of excellent information on vitiligo, treatments, research, and helpful products and services. They can create an account in just a minute or two and access many different forums and discussions, and they will begin receiving VSI's quarterly newsletters which are filled with the most current information available.

- They can also contact VSI directly by using VSI's [Contact Us](#). If VSI does not have the necessary information or resources on hand, we have a very broad network of vitiligo specialists to call on for additional support.

**If a person communicates that they are feeling depressed or suicidal, you should suggest that they seek medical advice as soon as possible.**

### ***Beware of Charlatans:***



Just as there are on the internet, there are people who go from support meeting to support meeting trying to peddle their wares and cures. Be very, very, careful if an unexpected guest begins talking about some miracle drug or treatment that they can help others obtain. If they begin passing out business cards, be sure you get one, then do your own research after the meeting. If you find that this person, or the product they're pushing is questionable, remove their

name from the email notification list and notify others of your findings.

### ***Meeting Follow-up, Updates, and Announcements:***

After the meeting, update your email list with any new addresses from the meeting. Be sure to include *all of those* who have responded by email on all correspondence, regardless of whether or not they were able to attend. This creates interest for upcoming meetings.

Write a short email about what a great time everyone had, noting a few highlights. If you decided on the date for an upcoming meeting, you can share that. Let them know that once a new flyer has been created, you will send it out to everyone so they can help spread the word.

### ***Email Distribution:***

It's quite simple to set up an email distribution list of all participants. If you have never done this you can find very simple instructions on the internet. Just search for "setting up email distribution list." If you only have a few names you can always enter them manually, just remember, out of respect for the privacy of your recipients, all emails should be sent using the "Bcc" (Blind Carbon Copy) format. Just because a person signed up to receive notifications *from you*, doesn't mean they are OK with a list of people they don't know seeing their name or email address.

To set up a Bcc email, simply use the support group email address in the "From" field, and in the "To" field, then add *all other recipients* addresses to the Bcc field.

From ▾	Supportgroupemail@gmail.com
To...	<a href="mailto:Supportgroupemail@gmail.com">Supportgroupemail@gmail.com</a>
Cc...	
Bcc...	all of your other email addresses go here
Subject	Vitiligo Support Group Meeting

**Be sure to check the support group email address regularly**, especially during the off months. If emails are not responded to, not only may you lose potential attendees, but you risk giving the impression of a very disorganized group. You might consider having email from the support group account automatically forwarded to an email address you check regularly – just remember to *always respond from the group account*, not your personal address.



After your group has become established and you have a regular group of attendees, during a meeting you might discuss the possibility of branching out and inviting guest speakers. The more members your group has, the more diversified their interests and backgrounds may be. Below are a few ideas to get you started:

***Dermatologist:***

Even if you've been unsuccessful finding a local dermatologist in a position to help, there may be resources within an hour or two who might be willing to help on an occasional basis.

VSI has a "Doctor Search" comprised of doctors VSI members have seen and liked. If you log on to your VSI account, you can access this page from the "Community" menu tab, and search for doctors by country, state, and city. Once you select a doctor, a page will open showing the treatments they offered at the time the information was submitted.

If you find a doctor offering treatments you think would be of interest to your group, give some thought to exactly what you would like the doctor to speak about, such as the different treatments offered and the type of response to expect. Then call the doctor's office, explain the situation and see if they would be willing to attend, and speak at a meeting.

***Mental Health Counselor or Psychologist:***

Most cities have a local mental health agency that can help you locate a professional to speak on topics such as relaxation, acceptance, and coping.

### ***Makeup Artist.***

You can use an internet search to locate local stores that carry corrective cosmetics. Give them a call and explain that you are calling on behalf of a vitiligo support group. You will likely need to explain that vitiligo is an autoimmune disease that causes pigment loss. Ask if they have any make-up artists with experience in this type of makeup application. If they respond that they do, ask the best time to reach that person. If after speaking with this person by phone they sound like a candidate for your meeting, it might be a good idea to arrange a time you could drop by the store for a demonstration. You could also ask if they could provide product samples and/or coupons.

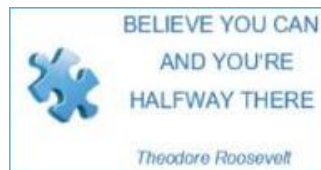
Many cities now have professional airbrush makeup artists who would be happy to provide a demonstration for your meeting. It would still be a good idea to try to meet with this person prior to the meeting to be sure they are able to provide the type of coverage needed for those in your group.

There might even be a person in your group who is skilled in covering vitiligo who would be willing to lead a demonstration!

For additional information on corrective cosmetics for vitiligo, click below to see VSI's Newsletter Article:

[\*Corrective Cosmetics: Tips for Vitiligo\*](#)

Do not be discouraged if your first couple of meetings only have a couple of people. It just takes time, patience, and legwork to get your support group off the ground!



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