



Interested in becoming a Support Group Leader? Here is some information to help you decide if this is the right volunteer opportunity for you!

Role of Support Group Leader (SGL)

Our Support Groups Leaders are vital volunteers for the Sjögren's Foundation. It is important that leaders create a welcoming and safe space for the sharing of experiences and connection of all members, both new patients and those with years of experience.

Since the Support Groups are an extension of the Sjögren's Foundation, our volunteer SGLs represent the Foundation on the grassroots, local level, and therefore leaders are required to be knowledgeable, up-to-date, and supportive of Foundation services, offerings, and events.

Important Aspects of the SGL Role

Provide:

- A supportive, positive, and uplifting atmosphere that allows for confidential and open discussions so that sharing of experiences can be safely fostered
- Support to patients *without* giving specific medical advice, referring patients to providers for medical advice when needed.
- Knowledgeable and up-to-date info on Foundation services, offerings and events.

Facilitate:

- Discussions in a way that allows all participants have a chance to share experiences, monitoring for discussion dominators
- Connection among group participants, welcoming all attendees and allowing for introductions

Encourage:

- Attendees to become educated and empowered patients by urging them to use the Foundation's educational resources such as website, books and attendance at educational events
- New patients to join the Foundation in order to receive the benefits of membership

Characteristics/Skills that affect being a successful support group leader:

- Experience living with Sjögren's (at least one year)
- Interest in continued learning about the disease
- Organized with administrative tasks
- Well-spoken with a professional demeanor
- Excellent communication skills- good listener, compassionate conversationalist
- Confidence to calmly and logically deal with occasional difficult people within a group
- Understanding of technology: can effectively & confidentially reply to emails, follow Foundation social media, and navigate webpage for resources. Also, be comfortable with zoom format for leading virtual meetings.
- Previous experience participating in and/or leading support groups
- An enthusiastic and avid supporter of the Sjögren's Foundation and their resources

New Support Group Leaders

Individuals looking to become new SGLs must:

- Be a member of the Sjögren's Foundation for *at least* six months, preferably one year
- Have been living with Sjögren's for *at least* one year
- Submit a Foundation-required application expressing his/her experience and interest in becoming a Support Group Leader. Application will be reviewed to ensure leaders will be a good fit for our program
- Be willing to have their information shared with patients in the Sjögren's community and on our website
- Be willing to host virtual meetings, even if they plan to host primarily in person
- Are preferred to have previous experience actively attending and/or leading support groups

Expectations of Active SGLs

To remain active, Support Group Leaders:

- Must remain a current member of the Foundation
- Ensure the Foundation always has their current phone number, mailing, and email address
- Take calls from area patients seeking support. Return patient telephone calls/emails as soon as possible, preferably within three (3) days
- Host *at least* 2 meetings per year, 4 or more is preferable
- Organize and/or delegate all meeting planning aspects including:
 - Dates and time of meetings
 - Choosing topics, recruiting any desired speakers and creating agenda
 - Working with the Foundation to promote meetings
 - Hosting of meetings- both virtual and live depending on the needs of the group and community

Benefits of being a Sjögren's Foundation Support Group Leader:

- A sense of pride, purpose and legacy in helping others with Sjögren's
- Increased circle of friends and connections with other support group leaders
- Support for yourself while also helping others in your group
- Discounts on Sjögren's Foundation educational events
- Early information on Foundation happenings

If you are interested in joining us as a Support Group Leader or have any further questions regarding this role please email the Sjögren's Foundation to discuss next steps. Email: info@sjogrens.org