

Participation doubles after lupus support group at HSS transitions to virtual format during pandemic

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A study at Hospital for Special Surgery (HSS) highlights the success of a lupus peer support and education group that transitioned to a virtual format during the pandemic. In addition to receiving high marks from group members, participation more than doubled after the meetings went remote.

"Studies have demonstrated the benefits of online peer support forums in [meeting](#) the [mental health](#), disease self-management and coping needs of people living with a [chronic illness](#)," explained Giselle Rodriguez, LCSW, social work program coordinator for Charla de Lupus (Lupus Chat) at HSS. "Although in-person meetings were no longer viable during the pandemic, the virtual groups offered an effective platform for patients to continue to meet with their peers, reduce isolation and expand the reach to additional family members at home and across the country."

Rodriguez presented the study, "Evaluating the Effectiveness & Impact of an In-Person Peer Support Group That Transitioned to a Virtual Platform During the COVID-19 Pandemic," at ACR Convergence 2022, the annual meeting of the American College of Rheumatology, in Philadelphia on November 12.

At the monthly support group, which has been ongoing at HSS since 2001, [social workers](#), rheumatologists and other [health care professionals](#) offer information on topics related to lupus, such as medications,

nutrition, pain management and research. The bilingual social work team translates all presentations into Spanish to distribute to Spanish-speaking members prior to the Zoom meetings. In addition, all communications in the chat box are translated live during the sessions to encourage Spanish speakers to participate. In some groups, simultaneous translation is provided.

To assess the effectiveness of the meetings, members received an [online survey](#) with multiple-choice and open-ended questions after nine virtual sessions from September 2020 to June 2021. Researchers conducted a comparison analysis with surveys completed by in-person groups held in 2018-2019 to assess reach, satisfaction, knowledge, coping and disease management.

Reach increased significantly after transitioning to a virtual group, with 373 participants versus 177 in 2018-2019. Responses highlighted the benefits of a virtual group, such as removing transportation barriers, the ability to join the meeting from anywhere and ease of participation by sharing a link. Limitations included inability to connect one on one, no internet access and challenges using Zoom.

Key findings:

- 99% of respondents reported satisfaction with the virtual groups
- 98% agreed that the groups increased their understanding of lupus-related issues
- 98% agreed the program met their expectations
- 97% agreed that they would recommend this group
- 95% agreed they could apply what they learned to manage lupus
- 93% agreed the groups helped them cope with lupus

No significant differences were observed when comparing most answers from in-person groups conducted in 2018-2019 to the virtual group.

However, in the virtual group, there was an 8% increase in respondents indicating that the sessions helped them cope with lupus.

Survey comments from participants demonstrated that they appreciated the virtual format:

"It was an excellent idea to transition from in-person programming to virtual. Charla should keep it virtual or a mixture of programming and virtual to keep it easy to attend all the meetings without missing any."

"Charla has made great use of Zoom for each of their programs. Although the experience is not the same as in person, every program was just as informative."

"I love the Zoom meeting since it is a way for everyone to stay connected from home healthy and safe."

"I would not have been able to attend the meetings due to location."

The monthly lupus support groups and special events continue to be hosted online through Zoom. Rodriguez and colleagues are assessing participants' interest in a [hybrid model](#) utilizing both in-person and virtual groups going forward.

Provided by Hospital for Special Surgery

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