

# Study shows volunteering benefits those with lupus

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Volunteers on the Hospital for Special Surgery's LupusLine®/Charla de Lupus (Lupus Chat)® counsel callers with lupus. Credit: Hospital for Special Surgery

Conventional wisdom has it that volunteering is good for you, and a study at Hospital for Special Surgery (HSS) shows that to be true for people with lupus volunteering in a peer support and education program.

The study, "The Effect and Psychosocial Impact of a Longstanding Telephone Peer Counseling Service on Volunteers with Systemic Lupus Erythematosus," was presented at the American College of Rheumatology/Association of Rheumatology Health Professionals annual meeting on October 22 in Chicago.

"Previous studies have demonstrated the value of peer counseling programs for people living with [lupus](#) and other chronic health conditions. In the current study, we set out to assess the impact on the volunteers themselves," said Priscilla Toral, LCSW, program manager of LupusLine/Charla de Lupus (Lupus Chat) at Hospital for Special Surgery. "We found that similar to the way the service helps callers, the counselor role positively impacts volunteers' ability to cope with and manage lupus and reduces isolation."

LupusLine offers [peer support](#) and education to people with lupus and their families. Established in 1988, the service is available to the public with a toll-free phone number. In addition to the United States, volunteers have counseled callers from Canada, Europe, South America, Jamaica, China and India.

The study found that in addition to having the opportunity to help others, counselors gained valuable knowledge about lupus from the 18-hour volunteer training program. Monthly seminars helped them work through challenges and provided a space for them to reflect on their illness.

"While having lupus may affect one's self-esteem adversely, being able to use this experience to help others can be empowering," said Roberta Horton, LCSW, ACSW, assistant vice president, Department of Social

Work Programs at Hospital for Special Surgery. "Volunteers also benefit from the feeling of mutual support, personal development, and further lupus knowledge gained through ongoing group meetings, educational seminars and individual supervision."

For their study, researchers distributed a 43-item online survey to volunteers. The counselors, all female, ranged in age from 30-79, with 30% between the ages of 60 and 69. They had served as a counselor for an average of 12 years.

The researchers reported the following findings:

- In terms of satisfaction, 91% of counselors indicated they were very satisfied with their role.
- The top reasons for becoming a counselor included an opportunity to help others affected by lupus (100% of respondents) and enhancing personal growth/development (73%).
- When asked about their reasons for continuing as a counselor, 82% said it was to meet others impacted by lupus and 73% identified the support of program staff.
- Most respondents (73%) reported that they had a better understanding of lupus since becoming a counselor.
- In relation to coping, 64% indicated that they have coped better with lupus since becoming a counselor.
- The majority of counselors (73%) reported feeling less alone since volunteering.
- Almost half of the volunteers (46%) reported feeling less depressed since becoming a peer counselor.
- When asked if monthly seminars help them to better cope with lupus, 78% agreed, and 89% of counselors reported that the seminars provide a space for them to reflect on their disease.

The volunteers indicated that the most rewarding part of their role was

"educational information that helps me understand lupus better" and "the opportunity to be outside of my own illness and connect with others."

"The study reinforces the two-way flow of psychosocial support received by counselors through their support of callers and ongoing connections with peers and program staff via monthly seminars," said Toral. "Our findings also highlight the continued relevance of a phone support service to people with lupus and opportunities for further research on the [volunteer](#) impact of peer-staffed programs."

Provided by Hospital for Special Surgery

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