

# Study shows lupus support line has positive impact

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A free telephone support and education program for people with lupus is a valuable resource to help them cope with the disease, according to a study at Hospital for Special Surgery (HSS) in New York City.

"At a time when technology is moving so quickly and we're moving to different modes of communication, our study shows that telephone communication is still a viable way to connect with people all over the world to support them and educate them about chronic illnesses such as lupus," said Jillian Rose, LCSW, MPH, assistant director, Community Engagement, Diversity and Research, Social Work Department at HSS. "The service, offered by Hospital for Special Surgery, provides callers with solid support by trained peer counselors."

The study on the lupus support line was presented at the American College of Rheumatology/Association of Rheumatology Health Professionals annual meeting on November 6 in San Diego.

LupusLine, established in 1988, is free and available to the public. People find out about the service through referrals from their physicians, lupus organizations, the Internet or word-of-mouth, and calls come in from around the world. In addition to the United States, volunteers have counseled callers from Canada, Europe, South America, Jamaica, China and India. The number of calls has more than doubled since 2005, averaging 80 to 100 per month.

A clinical social worker conducts an initial screening and assessment,

matching the caller with a trained volunteer and scheduling a time for the private counseling session. Many callers receive ongoing support on a weekly, biweekly or monthly basis. Counseling is available in English and Spanish. Services in Chinese are provided through another HSS program, LANtern.

"Volunteers, most of whom have lupus themselves, receive 20 hours of training to acquire skills related to counseling, support and active listening. Bimonthly seminars provide them with additional education," explained Priscilla Toral, LCSW, program manager, LupusLine and Charla de Lupus/Lupus Chat. "Four of the counselors have been with the support line since it was established in 1988."

"Lupus can be very isolating," said Rose. "Friends and families may not understand the illness, so it's very valuable for the caller to have a peer counselor, someone with similar experiences, who will listen and help to guide them."

To assess the support line, a 60-item survey was administered to callers matched with a peer-counselor between 2015 and 2017. It collected information on demographics, satisfaction with the screening process and peer counselors, lupus management, coping and the overall impact of the service.

The questionnaire was completed by 23 callers ? 72% of those contacted - ranging in age from 30-80, with 67% ages 40-59. When asked about their initial reasons for calling, 68% indicated they were seeking emotional support, as well as lupus education and resources.

The vast majority of respondents (95%) indicated that their expectations were met. Seventy-two percent noted that having someone knowledgeable about lupus was the most valuable aspect of the call. The majority of participants said the LupusLine helped them feel less

isolated, with one caller commenting, "I feel less alone."

#### Additional survey results:

- 95% of respondents indicated they were satisfied with their peer counselor match.
- 94% said they would recommend the service to others.
- 90% of participants were satisfied with the initial screening call with the social worker.
- 85% indicated that they have coped better with lupus since being counseled.
- 81% agreed they had a better understanding of lupus, and 88% respectively attributed this to utilization of the program.
- 66% reported feeling less depressed since starting the service, with a majority of these callers (78%) crediting LupusLine for this change.
- 52% had more than 12 calls with their peer counselor.

#### Provided by Hospital for Special Surgery

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