

Role of Community Leader Page

Experience shows that Community Leaders (previously known as “Experts”) are vital to the development of our virtual communities. Here are frequently asked questions about the role of Community Leader.

1) How will I find out when there is a question for me to answer?

You will receive a notification every time that someone has sent you a question. Once you click on the link, you will be taken to the question and, whenever you are ready to answer it, click on the relevant links. When done, press “Send” and the entry will soon be posted.

2) Are there any suggestions for how to go about answering questions?

Your role is not to dispense medical advice, and thus you must refrain from advocating for particular diagnostic tools, specific drugs, unconventional therapies, or recommending medical centers or physicians. Rather, your responsibility is to ensure that your community’s members have access to the knowledge that will empower them to find the most appropriate medical care and emotional support. Oftentimes the questions can be answered on the basis of information appearing on the Disorder Details and Disorder Resources pages. At other times, the questions are about issues that were covered in one of the Discussion Forum topics, so you may pick up material for your answer from them. You can also reach out to your community by starting a Discussion Forum Topic soliciting input (e.g., “Question on Dealing with Children” or “Question on Side Effects”) before attempting to answer a question all on your own.

For additional guidance, consult with your own physician and whichever disorder specialists you have had the opportunity to meet, or else you could try asking for advice from the authors of the most recent articles published on your illness. The email address of an article’s lead author is usually provided in medical and scientific journals, and a surprising amount of lead authors will reply to email messages as long as the question posed in an email message is succinct and a brief answer can be provided. Finally, there will be times when you may have to admit that there is no good answer or that you do not know the answer, but try to explain why this is so (e.g., “We do not yet know whether there is a genetic basis for this illness, because to my knowledge no such studies have been published”).

3) May I edit or summarize a question asked?

Yes, you are able to edit questions posed, and you should correct for typos, remove unnecessary or very personal details, omit offensive or disrespectful comments, and shorten questions that are long-winded.