



February 2019

Topics for February's call: Are leaders getting too many emails from organizations that go to our Us TOO website and take your addresses without getting permission from Us TOO home office? Ways to make new members feel comfortable and special. Suggestions for building relationships with local doctors. Humor helps.

Terri shared that it had been brought to her attention that some of the groups have been getting several emails and some phone calls from research firms, etc. People can go to the Us TOO site and get all of the group leaders emails and phone numbers. Terri shared that the only research firms we work with go through the home office first, and any emails that are sent out would come from her desk and not directly from the companies. When you get an email from Terri's desk requesting you to share with your email list, it is because we have a relationship with that company and work with them on the project. There is also typically some sort of donation that goes to Us TOO for helping them with their requests, and a stipend that is paid directly to the participants. It was discussed as to whether or not everyone felt that we should take the email addresses off of the Us TOO website so that they would not be public.

The large majority of the leaders on this call, and also several that responded to Terri's inquiry about this through email, felt that leaving the email addresses on the site is very important. Many people send emails asking about meeting times, topics, etc. If we take the email addresses off, the leaders feel it would be a disservice to the folks that we are trying to help. They can deal with the emails and just delete those that they are not interested in.

This led to the topic of being careful not to invite anyone to speak at your meetings who is trying to "sell" supplements or promote any specific drugs. There is a huge difference between educating on specific drugs and treatments and trying to "sell" you on using them, or promoting only one specific drug or treatment.

Steve Herman, a new leader from Scottsdale, asked the others what their basic meeting formats were. Many felt that one of the most important things is to be sure to introduce new people first. Cliff Whall from IL has a slide that he shows at the beginning of each meeting that encourages those to "tell us who you are and what is happening in your life/journey." It is important to always give the new person the floor.

Duane Kent from GA shares that many times the new folks will contact him first, before they come to their first meeting. This is a great way to get to know them ahead of time. Stick with them and follow-up with them if you know they are going for doctor's appointment, a new scan etc. This will make them feel more comfortable and hopefully encourage them to open up when they come to your meetings.

Duane also shared that a good way to build relationships with your doctors is to be sure to write them a thank you note after they speak. Ask the doctor if it would be ok to use him as a reference when asking other doctors to come and speak at meetings. If the doctor comes a few times a year, have a plaque made for the doctor, and take it to him at his office. Ask him if he can hang in his waiting room. It is also a good way to promote your group to others who visit that doctor!

Jerry Deans from Virginia, our Program Chair suggests we add something to the SGL resource section of the site on "how to treat the new guy."

Mike Hamlette from Friday Harbor, WA feels it is really important to have the more experienced men/caregivers share their stories/experiences with the new ones. This builds camaraderie and can help to give them HOPE! There is power in sharing!

Jerry Deans ended the call by sharing that humor helps! Laughter is a "reset" or a "shifting of gears" when having very serious conversations and can be good medicine!