

Patient Meetings How-To Guide

Are you hoping to start a regular patient support meeting in your area? Are you looking to educate yourself and others about the new progress being made in Kidney Cancer research? We're here to help you get started and make this as easy as possible.

- ❖ The first step is to decide what type of meeting would best meet your needs. Will this be a support meeting for patients, survivors, family members, friends, to talk about dealing with the disease and chance for all to share their stories? Or would you like to have featured speakers at every meeting?
- ❖ Next you need to decide where you want to hold your meeting. Depending on what type of meeting you are having will make a difference. If it's a support meeting and it's a small enough group, you could meet at someone's home, a coffee shop, or another informal location. If the groups a little larger try your local hospital, a Wellness Center, Gilda's Club or a library in your area. If a doctor is speaking, they may be able to secure a conference room in their hospital.
- ❖ If you're having any trouble securing a speaker (doctor, nurse, nutritionist, etc) or a location we will be happy to use our resources to help you.
- ❖ After a location and speaker are decided, you will need to coordinate with both to choose your date and time. Meetings are typically scheduled for 2 hours (first hour for speaker presentation, second hour for patient stories and discussion), but this can vary depending on location, speaker and you and the other patients needs.
- ❖ Once the date and time have been selected, let us know, as well as if a specific topic is going to be discussed and who, if any, your speaker is going to be. We will send out emails and/or postcards to all patients, family members, and survivors in your surrounding area. It will also be listed on the patient calendar on the Kidney Cancer Association web site.
- ❖ Now you will need to set your agenda for the meeting. You should determine with the speaker if he/she will answer questions during, before, or after his/her presentation. Also, decide if there will be an opportunity for patients to speak about their experiences and if so, where in the timeline this will fall.
- ❖ Think about whether or not refreshments should be served. Will you be bringing them or having someone donate them?
- ❖ Make sure you are familiar with the locations layout. What will the seating arrangement be, is there space for a sign-up table, refreshments (if having), where will the speaker be located.

- ❖ If any videos or power points are being shown, make sure that there proper audio visual (A/V) equipment is available to use at the location or that someone can bring it.
- ❖ We will send you any informational materials or kidney cancer awareness wristbands in advance, so that they will be available for those attending the meeting.
- ❖ When you arrive for the meeting, plan on showing up before the meeting starts to check on any A/V equipment being used, set up registration, and refreshments.
- ❖ Greet the patients, family members, and friends and have everyone sign in, take a name badge, and any other materials they would like.
- ❖ Make sure before the meeting has ended that you get some input from the patients.
 - How often would they like meetings?
 - Would they like a speaker at every meeting?
 - Let them know the KCA is here to help them in anyway that we can. We will do all we can to answer your questions.
 - Find out if anyone is interested in getting more involved: helping with meetings,
 - Fundraising, volunteering etc.

While it might seem a little overwhelming, please don't be discouraged. Remember that WE ARE HERE TO HELP YOU. The main goal of these meetings is to make sure that your needs and the needs of the other patients are met. This should be an opportunity for you to get together to talk about your disease and learn what you can do to treat it. If there is anything we can do to help please don't hesitate to contact us.

Please contact Juby Chacko if you are interested in trying to start a support group meeting in your area.

1-800-516-8051 or jchacko@kidneycancer.org