Starting a Support Group

Self-help or support groups provide a support system among people with common experiences. These groups, run by the members, meet to share common happenings, knowledge, strengths, and hopes.

The Carcinoid Cancer Foundation has gathered the following suggestions to assist people interested in starting their own carcinoid support group.

- First, talk with others who have successfully started support groups. Discuss what methods worked best for them and problems they encountered to help you avoid having similar troubles.
- A group can be formal or informal. An informal group can be as simple as taking turns meeting at someones home. For a more formal group it is wise to have some written policies to give to new members, including the group's purpose, meeting times, an explanation of how meetings are conducted, the groups policy on confidentiality, contact names to call with questions or concerns.
- Obtain a free, neutral meeting place. Try a community center, a medical center, YMCA/YWCA, library, church, synagogue or the Kiwanis, Rotary, Lions clubs. Some groups meet in restaurants (Dutch treat). If you choose a hospital, remember some doctors may be reluctant to send patients to the meeting if they don't practice at that hospital.
- Decide when and how frequently you want to meet. Weekend afternoons have been very successful for most carcinoid support groups. Also holding meetings at the same place and time each month (or other month) helps. Every other month seems to be a workable frequency.
- Ask members to provide their name, address, phone number, and any skills they feel they
 can contribute to the group: publicity, printing, organization, recruiting speakers, finding
 information.
- Meetings should have a structure so they don't wander off course and no one person monopolizes the group. Begin and end on time. Frequently members introduce themselves and state their reason for joining the group or share an experience.
- Put together a list of healthcare professionals interested in carcinoid. Call physicians, social workers, hospitals and public health workers and ask their help. These people can help you reach other carcinoid patients interested in attending a support group. They can't, by law, give you the names of patients. Create a flyer with your name, phone number, and date of your meeting, so they can give it to interested people.
- Publicity is important to your success. Place flyers in hospitals, doctors offices, the Health Department, community centers, place a notice or ad in a local paper. Internet Web announcements with carcinoid related organizations or Listserv Support groups are quick, easy and free ways to announce your meetings.
- Structure your first meeting to allow time to discuss what the members would like from the group. Shared leadership is easier than doing it all on your own. Each meeting should have an educational component, a time for business and sharing concerns, and setting a date for the next meeting. It is helpful to have activities for members such as: distributing flyers, shopping for a person who has just had surgery. Do you want to do fundraising?

Page 1 of 2

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- Discuss what members feel the group's responsibility to each other is. Address the issue of confidentiality such as things discussed at the meetings remains within the group unless someone is suicidal or threatening others.
- Speakers and experts on various topics of interest, carcinoid medical experts; in the fields of oncology, endocrinology, gastroenterology, radiology, and nutritionists, social workers, and nurses make the meetings interesting. Discussions may include diet, treatment, exercise, medical tests, dealing with insurance companies or employers. It is wise to have a healthcare professional attend each meeting.
- In short: **KEEP IT SIMPLE**. Adhere to the principles of *Simplicity, Consistency* and *Substance*

You can call the Carcinoid Cancer Foundation to provide you with a supply of updated information written by carcinoid specialists to ensure group members have correct information. 1-888-722-3132

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