

ThyCa: Thyroid Cancer  
Survivors' Association, Inc.

[www.thyca.org](http://www.thyca.org)

**Manual:**  
**Starting a Thyroid Cancer Survivors'**  
**Organization**

March 2010



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**ABOUT ThyCa: Thyroid Cancer Survivors' Association, Inc. ([www.thyca.org](http://www.thyca.org))**

**ThyCa: Thyroid Cancer Survivors' Association, Inc.**, is a national non-profit 501 (c)(3) organization of thyroid cancer survivors, family members, and health care professionals. We are dedicated to education, communication, support, awareness for early detection, and thyroid cancer research fundraising and research grants. ThyCa provides a wide array of free education and support services, as well as numerous downloadable publications and special events throughout the year. For more information and free materials, visit our web site at [www.thyca.org](http://www.thyca.org), call toll free at 1-877-588-7904, write to ThyCa: Thyroid Cancer Survivors' Association, Inc., P.O. Box 1545, New York, NY 10159-1545, or e-mail to [thyca@thyca.org](mailto:thyca@thyca.org).

## Dedication

ThyCa dedicates this manual to the 17 original people who recognized a need for an organization to provide support and education for thyroid cancer survivors, families, and the public. Beginning early in 1995, they came together to create ThyCa: Thyroid Cancer Survivors' Association, Inc. Thank you to the ThyCa Steering Committee. Original members included Ric Blake, Gary Bloom, Kathy Buetikofer, Paige Drymalski, Karen Ferguson, Gail Gundling, Brian Hughes, Dr. Arturo Rolla, Jerry Sachs, Jan Scheurman, Rees Shamansky, Marilyn Sherman, Betty Solbjor, Eric Vahlbusch, Marci Vanim, Lisa Warner, and Mary Rose Weckerle.

Because of their efforts, and the efforts of all who have come together since, ThyCa has created a warm and welcome environment for so many to come together and feel part of the ThyCa community of thyroid cancer survivors,

## Welcome!

Thank you for your interest in starting a thyroid cancer survivors' organization.

In this manual, we share the experience of ThyCa: Thyroid Cancer Survivors' Association, Inc., over the past nearly 15 years since early 1995. Please use the information and suggestions that will be of most help to your organization and your circumstances.

You have made the important decision to share your experiences of your own thyroid cancer, and to help educate and support others affected by this disease. In this way, we hope that you will be able to help others receive the emotional support we all need when given a diagnosis of cancer. At the same time you will receive support in return.

The goals of an organization are to:

- Create a warm and comfortable setting which allows all to share their stories and issues;
- Meet other thyroid cancer survivors and caregivers, in person, by phone, and/or by e-mail;
- Provide emotional and educational support;
- Share common experiences;
- Discuss our treatment protocols and medical issues;
- Identify useful resources (electronic and print); and
- Get information on who the thyroid cancer specialists are in the area.

We hope that this manual will be of help to you. If you have any suggestions or questions, please contact us.

Please let us know if there is any other information or materials or resources you need for your organization's success.

Sincerely,  
*Gary*

Gary Bloom  
Executive Director  
ThyCa: Thyroid Cancer Survivors' Association, Inc.

# ThyCa: Thyroid Cancer Survivors' Association, Inc.

[www.thyca.org](http://www.thyca.org)

## Manual: Starting a Thyroid Cancer Survivors' Organization

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# 1. Starting a Thyroid Cancer Survivors' Organization

As you consider developing an organization for thyroid cancer survivors and their loved ones, first determine whether there is already an organization in your country. You can do this by contacting cancer support groups, hospitals, medical professionals, and by doing an Internet search to see if an organization already exists. These contacts may also know thyroid cancer survivors in your area who would be interested in becoming involved in the new organization.

If there is already an organization, start by reaching out to this group. Ask if you can work together, perhaps to help develop additional services and be part of one organization.

If there isn't already an organization, ThyCa wants to help. We believe you will find it easier to use what has been used successfully before. We're here to share what we've learned. We hope that it will make your development effort easier and faster.

First, identify your goals. You may choose to start with one or two goals, and add to them as time goes by. Although goals may vary, they should include some or all of the following:

- Developing and providing accurate, understandable information about thyroid cancer.
- Giving emotional support to thyroid cancer survivors and their loved ones.
- Increasing public awareness about thyroid cancer.
- Creating a list of thyroid cancer specialists in your area.
- Fundraising for thyroid cancer research.

While you will want to try and define your goals, be flexible. Don't try to attach numbers to your goals; you will do that later when you set objectives toward achieving the goals. Start small and build on each success. Don't undertake too much at the beginning. The objectives and priorities of your organization may change and may grow over time.

## Steps to take

- While it is possible for one person to develop an organization, it is definitely easier if you know at least two or three other committed thyroid cancer survivors who want to work together to create an organization to help others. If you don't know anyone, ask your doctor, he or she may know of someone who is motivated to get involved. ThyCa began when its 17 co-founders discovered each other through contacts over the Internet, as well as personal contact with the physician who helped start the organization.
- You don't need medical advisors to get started; however, over time, you will want to identify at least one physician to act as medical advisor and to ensure accuracy of any medical information produced by your organization. Start by reaching out to the physicians of the organizational team.
- **You may utilize any material found on the ThyCa: Thyroid Cancer Survivors' Association, Inc. ([www.thyca.org](http://www.thyca.org)) web site, or any of our print materials. We only ask that you acknowledge credit to ThyCa: Thyroid Cancer Survivors' Association, Inc. ([www.thyca.org](http://www.thyca.org)).**

- Media. In some cases, you will be able to identify free opportunities through the Internet and through media such as television, newspapers, and radio. Start through word of mouth, through people and physicians you know.
- Over time, you may want to add a telephone Response Line. At that time, you will need a telephone and voicemail system or a telephone answering machine. You will also need one or more volunteers to return phone calls; over time, you may need a large team of volunteers. A telephone response line is an example of a service that you can add over time. Remember, don't try to start too many services all at once.
- You will need to create corporate documents and follow the regulatory guidelines required in your country. In the United States, these include Articles of Incorporation, and Bylaws to formalize the organization and become a tax-exempt nonprofit organization in order to more easily raise money. If you decide to go this way, do an Internet search to find sample documents, go to the library, go to a law school and seek out expert assistance, perhaps from a volunteer attorney or other expert appropriate in your country. Contact another health-related organization in your country and ask them for assistance. Ask whether you can copy or adapt any of their relevant documents related to the legal technicalities, and change the appropriate words/phrases. Given your mission of being a small organization, and non-profit, you hope that you will not have to pay for this service. There are experts available in many communities who are willing to donate their time.
- Over time, you may need the help of an attorney to help you complete the formalities required for a charity and, if this is an option in your country, to obtain tax-exempt status to help you collect donations.
- Your expert advisor will also be able to assist you on matters such as developing your board of directors and committees, and ensuring compliance with the regulations of your country.
- Over time, you may also need to obtain liability insurance to protect you and your membership.
- As a health-related organization, protecting your constituents' privacy is another matter that requires careful attention. This is for the wellbeing and support of everyone who is in contact with your organization.

### **Challenge**

You may decide that it isn't feasible to create a patient organization that is dedicated only to thyroid cancer in your country. This type of organization can exist in countries with a well-developed tradition of patient support groups. However, in countries where this tradition does not exist, it may be a difficult challenge. While it may be more of a challenge, that doesn't mean it isn't a worthwhile effort. This challenge is a reason to start out slowly, and think small with the intent of adding services, instead of starting large, and finding it difficult to sustain services.

### **Consider Meeting in Person**

One option to consider is holding a face-to-face meeting of interested people. Gather a group through an Internet announcement, as well as through flyers distributed to physicians saying, "Thyroid Cancer Survivors meeting to discuss forming an education and support organization for survivors, and caregivers dealing with a thyroid cancer diagnosis. If you are interested, please contact us at: *provide your name, telephone number, and your e-mail address*." The meeting should be held in a public place to make sure that everyone is comfortable meeting each other.

At this initial meeting, everyone introduce themselves, and state why they are there and what their vision is.

Someone should volunteer to take notes. Over time, someone should step forward to lead the meeting, although everyone's thoughts and ideas should be shared. If no one steps forward to lead, the group should choose one of its members as meeting leader.

To gain momentum, another possibility to consider is organizing an education and support meeting with a physician speaker or speakers. Publicize the meeting several weeks in advance via e-mail and flyers announcing the speakers, agenda, date, time, and meeting location. If you decide to do this, be sure to keep an attendee list in order to stay in contact (names, addresses, telephone numbers, e-mail addresses). Some of these attendees may step forward to volunteer.

### **Support and Educational Materials Available from ThyCa**

ThyCa will provide samples of our brochures, newsletters, announcements, and forms such as signup sheets, as well as a list of potential discussion topics for thyroid cancer support group meetings. This manual includes a few of these.

We will also try to help with development of your organization's infrastructure paperwork. Our materials are relevant in the United States, and therefore may not be helpful in your region of the world. We encourage you to seek out assistance in your own country. We will also give you English language books that have been written for thyroid cancer survivors. If you would like to translate these materials, you will need to get written permission from the organization, author(s), or editor(s) and indicate in your literature that it has been "translated by permission of \_\_\_\_\_", then include the name of the originating group. ThyCa grants permission to copy our materials into your native language. We do ask that you provide appropriate acknowledgment of ThyCa: Thyroid Cancer Survivors' Association, Inc.

### **Financial Support**

It's a good idea to get someone to act as Treasurer early in the development process, and to start financial recordkeeping and a bank account for the thyroid cancer organization. Until your organization gets the appropriate tax-exempt status in your country gifts will not be tax-deductible. This may make it harder to raise funds. You will likely need legal assistance to achieve this status.

If your efforts are to increase public awareness about thyroid problems, you should do fundraising early. Sometimes a pharmaceutical company which makes thyroid medication will give financial and other support, such as brochures and other written information for thyroid patients.

## **Participation of Specialists**

Everyone associated with the thyroid cancer survivors' organization needs to understand that only physicians can give medical advice. Patients and caregivers share encouragement, understanding, experiences, and hope. However, we do not give medical advice.

## **Requests for Information**

When someone contacts your organization, by e-mail, phone, or postal mail, reply promptly. Provide relevant information, as well as flyers, and brochures, describing your organization's mission and goals. List your organizations services, which may include: written information, educational programs and a telephone response line (if you offer this service). Indicate additional programs that you would like to develop when you have the volunteers and funding. This may help you find interested and qualified volunteers.

Good luck and best wishes from ThyCa for what you are undertaking to help thyroid cancer survivors. Remember it takes time to develop services, so be patient.

## 2. ThyCa Experience

From the outset, ThyCa has been the beneficiary of tremendous support within the medical community. ThyCa's physician advisors offer their expertise for our web site's medical content, our print materials, as speakers at our support group meetings, regional workshops, and annual conference, and in devoting time to doctor-to-doctor networking about ThyCa with their colleagues. They have also actively supported our effort for greater public awareness of thyroid cancer and acceptance and visibility of ThyCa within the medical community.

**Our greatest strengths are the personal attention we give to other survivors and families and, because thyroid cancer too often is complicated or fatal if treatment is delayed or inappropriate, that we provide accurate and timely information.**

### Lessons Learned and Future Needs

- We know that all our volunteers, including our board members, all have personal lives and commitments in addition to their ThyCa commitment. Additionally, we go through treatments and testing that sometimes render us temporarily unable to manage our volunteer work. So we have to continually increase our volunteer strength to include enough volunteers to fill in, build strong committees, provide back up, and take up the slack as well as to help us continue to grow to be able to serve more people.
- Our support group facilitators, toll-free telephone-support team, e-mail team, and our Person-to-Person Network volunteers must follow specific guidelines common to all nonprofits providing services related to health care. Most important is that we don't provide medical advice, because we are not physicians. We offer support through listening and sharing experiences. We encourage support groups to invite thyroid cancer experts to participate periodically. We believe that this is helpful to both the group and the medical professional.
- Our annual survivor and family conference has been a tremendous success in allowing survivors the opportunity to meet and talk at length with thyroid cancer specialists.
- We are eager to borrow or adapt infrastructure and committee and service development from any and all organizations that have walked the path before us. And, equally, we are enthusiastic about sharing with those who follow us.

As a support organization, we expect to remain primarily volunteer-based even as we seek to raise funds for more outreach and a small staff. We have many volunteers who contribute 8 to 20 hours each week, and some contribute more. After ThyCa's first 12 years (1995-2007), we had grown to the point that we needed a fulltime management staff person to manage services essential to ThyCa's continued functioning and further growth and development. ThyCa funds are used primarily for thyroid cancer research and, beginning in September 2007, to support one paid position, an Executive Director. ThyCa started with a small number of volunteers and now has more than 300 volunteers, some helping year-round and some giving one-time or occasional help.

## **The Relationship Between ThyCa and Your New Organization**

The relationship between ThyCa: Thyroid Cancer Survivors' Association, Inc. and each local or other national survivors' organization is strictly limited to those matters contained in this Manual. Each local survivors' organization is a separate, independent entity that is not controlled by ThyCa and to which ThyCa seeks to provide helpful information and support.

Local organizations are initially organized by a local volunteer or volunteers, usually a thyroid cancer survivor or survivors. Local volunteers are either thyroid cancer survivors or professionally trained facilitators from a local healthcare institution or organization.

## **Space for Your Face-to-Face Meetings**

ThyCa encourages volunteers to secure available meeting space that is free for public use. You may find such space in: libraries, hospitals, cancer centers, schools, churches, civic centers, colleges, health-related organizations, and other community organizations, etc.

## **Budget and Expense Reimbursement**

- The goal is education, support, and communication in a simple format.
- Your cash budget initially should be close to zero (probably less than \$20 in U.S. dollars).
- Ask around for donations of funds, of in-kind assistance with mailings, with printing materials. ThyCa will share its printed materials with you at no cost.
- Occasional guest speakers should donate their time.
- Publicity costs nothing, and can be done mostly by e-mail, flyers and local phone calls. You do not need to use paid advertisements. Newspapers, magazines, newsletters, radio stations, and television stations may give you free space or time for public service announcements.
- If you have face-to-face meetings, it is not necessary to provide snacks at meetings. You're providing an important and valuable service. You don't need to supply food as well. People will attend for the benefit of the support and education.

## **Ways Groups Avoid Financial Costs for Meetings, Seminars, and Workshops**

Volunteers are the keys to a successful meeting or workshop. To summarize the key ways to avoid costs:

- Free meeting site.
- Volunteer speakers.
- Outreach and publicity at no cost, using varied channels, especially e-mail.
- Print materials and forms donated by local businesses.
- In-kind donations of refreshments and supplies. It is not necessary to purchase gifts for attendees or speakers.

## 3. Support Group Meeting Guidelines

The role of the facilitator (leader) of a ThyCa Support Group Facilitator is simple: Make sure participants are comfortable, have a chance to ask the questions they need to ask and share as much as they are willing to share. We do this by creating a warm and inviting atmosphere at Support Group meetings and by listening more than we speak.

**Seating:** Sitting in a circle makes it easier to hear and see everyone, and it feels friendlier.

**Time:** The length of the meeting is up to the organizers. Most groups meet for 90 minutes.

**Day of the week:** In the U.S., the best day to meet is probably later morning or early afternoon on Saturday or Sunday.

**Special Schedule Considerations:** For those members, especially new members, who are hypothyroid and are working at jobs during the day, or have child care responsibilities, meeting in the evening after work is difficult at best. Meeting on Saturday or Sunday means that some thyroid cancer survivors may not be able to attend for religious reasons.

**Atmosphere:** The facilitator should strive to make the "feel" of the room as friendly as possible. Keeping the lights lower and using non-fluorescent light helps. The meeting space should be a place of nurturing and welcoming.

**Food and Other Comforts:** Having healthy snacks and a beverage helps make the atmosphere welcoming, but the facilitator is NOT responsible for food and drinks. The members of the group are responsible; if they want it, let them help by bringing in snacks and beverages. They'll feel as though they're contributing and you won't feel burdened.

**How many facilitators?** Two co-facilitators is ideal for a group. It's important for one facilitator NOT to carry the full responsibility of the group. Having co-facilitators makes it easier to handle vacations, illness, and the need for some time off.

**Other tasks:** Usually, one or two facilitators can manage all the tasks necessary to maintain and nurture a local support group. However, it helps to avoid burn-out of volunteers and ensure continuity in case of illness to invite others from the group to take responsibility for some tasks. It also helps people feel as though they are a part of something. These tasks include:

- Contact Person or Persons – this person's name, phone and e-mail are listed in all promotional material, and publicity for the group;
- Facilitator – facilitates each session;
- Publicist – handles all the publicity and outreach;
- Site Coordinator – liaison between the group and the meeting location.
- Historian – this person keeps the history of the group. This doesn't have to be extensive. Includes the date and place the group started, samples of flyers and press releases, articles from local media, annual membership lists and the names and addresses of the group's facilitators and other volunteers.

**Meeting Format:** The facilitator of the first ThyCa support group, which began in November 1996, followed the model he had observed at The Wellness Community's support groups.

Participants introduce themselves and talk about their thyroid cancer history. The facilitator ALWAYS begins first because most people feel uncomfortable talking in a group at first.

Facilitators should not encourage the introductions to go around the circle, but let people start when they're ready, from wherever they are seated in the circle. Many people can't listen to what is being said if they feel the pressure of being next "in line" to talk. Additionally, moving around the room allows someone to not participate if they prefer.

**Meeting Structure:** The overall structure for the model above then is: (1) introductions, beginning with the facilitator(s), (2) followed by others in no particular order.

If there are at least three or four people in a session, the conversation will go where those present want it to go. Other than making sure each person has a chance to talk and no one monopolizes the floor, the less structure the better.

ThyCa provides a series of discussion topics in the event that participants aren't feeling particularly talkative.

**Advice:** The official policy of the ThyCa Board of Directors is that the organizers and facilitators of local support groups affiliated with ThyCa do NOT give medical advice. Nor do they endorse medical treatments not endorsed by ThyCa's Medical Advisory Board.

However, the fact is that as members of a group become friends, they may offer suggestions or advice to each other and to new members of the group.

The facilitator, however, should always make sure that each suggestion is followed by the suggestion for the participant to see her/his doctor or get a second opinion from their own medical professional before making any decision about treatment.

**Guest Speakers:** ThyCa encourages groups to invite guest speakers to participate at group meetings. ThyCa recommends inviting physicians and others to present on medical topics, physical therapists and others to present on coping and complementary approaches, and inviting representatives from pharmaceutical firms and/or medical equipment manufacturers to discuss insurance/access issues.

**Outside Facilitators:** One possibility is to have a professionally trained facilitator who facilitates the group as part of her/his work or simply as a way to support your efforts. Hospitals, teaching centers, such as medical schools, and other organizations may have facilitators available. However, it is important not to spend too much time looking for a professional to facilitate. After all, it's important to have a safe and comfortable place for those newly diagnosed or facing treatment for the first time, a place where they can find others who've had similar experience.

Some organizations and many institutions will not permit support groups to meet unless one of its trained facilitators co-facilitates the group. In many cases, this is to limit the organization's risk for liability. Some ThyCa support groups are led by hospital staff members; most ThyCa groups consist of survivors and caregivers dedicated to helping ourselves and others.

**Who may attend?** Local ThyCa Support Groups are open to all survivors of thyroid cancer, as well as family members and interested friends. Survivors are defined in the broadest sense: those with the disease, their families, friends, colleagues and care givers.

If groups are large enough, members may wish to separate into two groups for part of the session: one for those with thyroid cancer and one for their friends and families. Separate groups are often very helpful for spouses and significant others to have a chance to talk with others having similar experiences.

Each group will decide if those who are not thyroid cancer survivors or caregivers may attend (students, physicians or other healthcare professionals). Occasionally, someone with a related thyroid condition (hypothyroidism, for example) may ask to attend; each group should establish its own policy.

## 4. How ThyCa Helps Facilitators

ThyCa will help local support groups in the following ways:

1. Provide training for all new facilitators
2. Provide business cards, group flyers, news releases, and a Facilitator tool-kit, including a Support Group Facilitator manual, for each support group facilitator
3. Create a web page for each local support group on the [www.thyca.org](http://www.thyca.org) web site
4. Support local groups in its promotional campaigns
5. Provide an experienced facilitator mentor as a resource to new facilitators
6. Conduct a workshop for facilitators at the annual conference
7. Make available templates of press releases, flyers and posters facilitators can adapt for local use
8. Make available sample letters sent by ThyCa and other facilitators to physicians and organizations
9. Provide thyroid cancer informational materials to distribute at meetings
10. Invite facilitators to join the Support Group (Yahoo Group) listserv for ThyCa communication to all facilitators and facilitator communication and networking with all facilitators
11. Share information of new ThyCa services, educational opportunities, items, etc.

## 5. ThyCa Facilitator Mentor Program

**Purpose:** Provide support and guidance to a ThyCa facilitator during the first year of their facilitation.

**Expected Outcomes:**

1. Both mentor and facilitator will describe this program as beneficial.
2. The ThyCa community will be stronger.

**Definition of a Mentor:** trusted counselor or guide; also: TUTOR, COACH

*Tutor:* to have the guardianship of; to teach or guide individually; to receive instruction especially privately

*Coach:* to instruct, direct, or prompt as a coach; one who instructs or trains a team of performers.

*Source: Merriam-Webster's Desk Dictionary, 1995*

**Program Overview:**

Facilitators wanting to become a mentor may be referred by a ThyCa volunteer, ThyCa support group person or self-referred to the ThyCa Support Group Coordinator.

ThyCa mentors should have at least one year of active facilitation of a ThyCa Support Group and demonstrate ThyCa facilitator skills.

- Actively listens to others
- Supports thyroid cancer patients and caregivers
- Provides welcoming and open atmosphere in support group
- Provides accurate thyroid cancer information and not personal advice
- Respects dignity and worth of others
- Shares personal thyroid cancer experience to benefit others

Mentors provide support for one year. ThyCa Support Group Program Coordinator provides the mentor the facilitator's application which includes contact information and the new support group web posting.

Mentor should contact new facilitator at least 6 times in the first year. Contacts may be made by via e-mail, phone, or in-person. Possible contact times may include but are not limited to:

- Before first support group meeting
- At first support group meeting (in-person)
- After first support group meeting
- Monthly after first support group meeting for three months
- At end of 12 month period

The ThyCa Support Group program coordinator will contact the facilitator and mentor to assess the benefit rating at least once during and at the end of the one year term.

## 6. Suggested Support Group Meeting Agenda

### **SETUP:**

1. Put up signs throughout the facility to direct attendees (**remember scotch tape**)
2. Put out the sign-in sheet and pens – we encourage all folks to sign-in (update info) so we can contact you (as well as contacting each other)
3. Put out nametag stock (suggest plain white 2"x4" stickers with a dark marker)
4. Bring slide projector, dry markers and eraser for outside speakers
5. Put out any literature to share (bring enough for all). Explain any pertinent handouts.

### **OPENING:**

1. Thank you all for attending this meeting of the ThyCa Support Group. My name is \_\_\_\_\_ and I'm in my \_\_\_\_\_ year as a thyroid cancer survivor.
2. Is it ok to take notes? It's ok to take notes for personal use only. What's said here stays here!
3. Some of you know each other and some of you don't. We encourage people to speak outside of group.
4. You don't have to participate if you don't want to!
5. Introduce yourself.

### **MEETING/DISCUSSION:**

1. **Please tell us who you are**, why you're here, how you feel, what you want from the group
2. See suggested discussion topics section

### **CLOSING:**

1. In closing, what worked? What didn't work? Please make suggestions, either now or privately.
2. Mention ThyCa Annual Conference, Regional Workshops, Future Guest Speakers.
3. Mention Support Group affiliation with ThyCa: Thyroid Cancer Survivors' Association, Inc. and ThyCa's need for volunteers.
4. ThyCa membership: form of fundraising! Provides membership newsletter, I.D. card, notification of events and a discount on conference registration.

Invite attendees to help spread the word by posting flyers and brochures at their workplace, community groups, libraries, congregations and other places.

## 7. Discussion Topics

1. Medications, adjusting/managing: triiodothyronine (T3), levothyroxine products (T4), Thyrogen (recombinant TSH)
2. Adjusting to thyroid cancer / problems
3. Doctors
4. Did family/friends treat you differently...how did you deal with this? Do these relationships recover?
5. Do you get help from people you previously considered acquaintances?
6. Do people's comments make you mad? Have you told people their comments were inappropriate or hurtful?
7. Has your attitude toward co-workers and/or work in general changed? What other work issues have you experienced?
8. How do you deal with co-workers who 'don't get what you're going through'?
9. Hypothyroid versus Hyperthyroid Status
10. Low Iodine Diet
11. Newly diagnosed and dealing with thyroid cancer problems for the first time
12. Describe your personal stories and experiences
13. Pre-Surgery anxieties
14. What was your Radioactive Iodine (RAI) dosage?
15. Reaction to the ThyCa Meetings?
16. Scans: Radiation, CT, MRI; going through the process and technical information
17. Scarring
18. Adjusting to the "C" word

## 8. Support Group Jobs

**Facilitator:** help run the meetings, ideally 2 people (primary and backup). Makes sure the site is ready for each meeting; conduct the meeting being sensitive to: patient life stage, male versus female issues, disease stage: newly diagnosed, post surgery, pre-therapy, post-therapy. *2.5 hours per month*

**Site management:** site setup and cleanup. *30 minutes per month*

**List management:** maintain a list of all attendees and follow-up as necessary in MS Access (database program) or MS Excel. *30 minutes per month*

**Phone Tree:** contact folks without e-mail. *1 hour per month*

**Publicist:** handles all the publicity and outreach, including writing to the newspapers and local area docs. *30 minutes per month*

**Contact Person:** this person's name, phone and e-mail are listed in all promotional material and publicity for the group. *2-3 hours per month*

**Site Coordinator:** the person who is the liaison between the group and the site. *30 minutes per month*

**Snacks:** coordinate it if you all want them. *30 minutes per month*

## 9. Suggestions on Publicizing Your Support Group

Use e-mail, sent as bcc (blind copied, so that recipients do not see each other's e-mail addresses, to your personal networks. Put announcements in newsletters of community groups with which you're affiliated. Put flyers on bulletin boards in community locations. Check your local newspapers and online Internet sources for support group or health calendars

Send flyers and introduction letters to area doctors.

Send flyers and introduction letters to local hospitals.

- Ideally, address them to a specific person in the Departments of Nuclear Medicine, Endocrinology, and Social Work.

Contact the Health editor of your local newspaper and see if they will run an article on your group. Post flyers and brochures in community locations – libraries, supermarkets, pharmacies, religious congregations, community centers, workplaces, etc.

Please use or adapt the sample publicity documents on the following pages. Many newspapers require as much as three (3) weeks advance notice for inclusion in the Health Calendar Section. Some newspapers accept e-mail announcements.

### Sample News Release - E-Mail or Print

RE: Chicago's First Support Group for Thyroid Cancer Survivors Begins Meeting February 20, 2001

Date: \_\_\_\_\_

Release Immediately

Released by ThyCa: Thyroid Cancer Survivors' Association, Inc.

Web site <[www.thyca.org](http://www.thyca.org)>

Media

Contact Mary Smith <[mary-smith@thyca.org](mailto:mary-smith@thyca.org)>

Phone number and e-mail contact

Address ThyCa: Thyroid Cancer Survivors' Association, Inc.

PO Box 1545, New York, NY 10159-1545

Toll-Free Survivors' Number: 877-588-7904

Fax: 630-604-6078

E-mail: [thyca@thyca.org](mailto:thyca@thyca.org)

Local Contact: \_\_\_Name \_\_\_ / \_\_\_phone number / \_\_\_e-mail@thyca.org

Greater Chicago's first support group for thyroid cancer survivors will begin meeting at the Cancer Care Center in Park Ridge, Ill., on February 20, 2001. Organized by ThyCa: Thyroid Cancer Survivors' Association, Inc., ThyCa Chicago is free and open to all thyroid cancer survivors and their families.

ThyCa Chicago meets from 7 to 9 p.m. on the third Tuesday of each month in Room 2220 at the Cancer Care Center, across from Lutheran General Hospital, 1700 Luther Lane, Park Ridge. For information about ThyCa Chicago, call \_\_\_\_\_ at \_\_\_\_\_ or write Chicago\_IL@thyca.org.

Support groups for thyroid cancer survivors are organized across the United States by ThyCa: Thyroid Cancer Survivors' Association, Inc. ThyCa is a nonprofit, volunteer organization providing services and resources to thyroid cancer survivors and their families at no charge. For more information call toll-free 877-588-7904, write to PO Box 1545, New York, NY 10159-1545, e-mail to [thyca@thyca.org](mailto:thyca@thyca.org), or visit the web site at <http://www.thyca.org/>.

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### **Sample Letter to Health Care Professionals**

*<printed on ThyCa letterhead>*

Dear Health Care Professional:

We at ThyCa: Thyroid Cancer Survivors' Association, Inc., would like to take this opportunity to introduce ourselves, to thank you for the care you provide for thyroid cancer patients, and to give you some materials to share with your patients.

Although most thyroid cancers are not life-threatening unless they go untreated, thyroid cancer, like all cancer, is life-changing. Cancer support groups can be of great benefit. Emotional and social support from others undergoing similar experiences helps patients and their families cope with the stresses involved.

In a thyroid cancer support group meeting, we share encouragement and understanding. We do not give medical advice. ThyCa's mission is to provide support to patients, their families and friends, and caregivers. Our free support services include our local support groups, e-mail support groups, our person-to-person network, a toll-free number, and our Internet web site at [www.thyca.org](http://www.thyca.org).

We invite you to make the enclosed brochures available to your thyroid cancer patients. If you need more brochures, please let us know and we will be happy to send them to you.

We greatly appreciate the care and treatment you provide, and hope that our free support will also benefit your patients and their families. Thank you for your time and consideration.

Sincerely,

ThyCa: Thyroid Cancer Survivors Association, Inc.

P.S. To order more brochures (free), please e-mail your complete mailing address to [brochures@thyca.org](mailto:brochures@thyca.org), fax to 1-503-905-9725, or write to ThyCa Brochures, P.O. Box 1545, New York, NY 10159-1545

### Sample E-Mail Reminder Notice

This is a reminder about the next meeting of ThyCa Washington, DC, which will meet Saturday, April 21<sup>st</sup>, from 10:30 a.m. to noon in the second floor Private Dining Room #2 at Holy Cross Hospital.

The ThyCa Washington, DC is a mutual support group open to all thyroid cancers survivors, their family and friends. We're a friendly place to talk with and learn from other thyroid cancer survivors.

I'd also like to quickly remind you about the upcoming Thyroid Cancer Survivors' Conference October 17-19, 2008 in St. Louis, Missouri. This meeting is a great resource for all thyroid cancer survivors and their caregivers. For more information about the conference go to: <http://www.thyca.org/conferences.htm> or call me: 301-555-1212.

Please make sure to read all the way down this long e-mail ... there's good info all the way through! And, don't forget to check the ThyCa web site for new information from time to time.

Hope to see many of you in the months to come,

John Smith  
ThyCa Washington, DC Facilitator  
[Washington\\_DC@thyca.org](mailto:Washington_DC@thyca.org)

ThyCa Washington, DC  
Meets: 3rd Saturday of each month, 10:30 a.m. to noon  
Place: Holy Cross Hospital  
1500 Forest Glen Road  
Private Dining Room #2, 2nd Floor of the main hospital in the cafeteria  
Silver Spring, MD 20910  
Georgia Avenue North exit off 495; Forest Glen Metro Station  
Contact: John Smith  
e-mail: [Washington\\_DC@thyca.org](mailto:Washington_DC@thyca.org)  
phone: 301-555-1212  
fax: 630-604-6078  
Group's web page: <http://www.thyca.org/sg/dc.htm>

----- Directions to ThyCa Washington, DC

From the NORTH and SOUTH

From 495 take Georgia Avenue exit north to Forest Glen Road (first traffic light off the beltway). Holy Cross will be on the right about a half mile down the road.

From the METRO

Take the red line toward Glenmont. Get off at Forest Glen. Cross Georgia Avenue. Continue approximately half mile. Holy Cross will be on the right.

----- Schedule for ThyCa Washington, DC

Every third Saturday at 10:30am in the Physician Dining Room.

April 21<sup>st</sup>  
May 19<sup>th</sup>  
June 16<sup>th</sup>  
July 21<sup>st</sup>  
August 18<sup>th</sup>  
September 15<sup>th</sup>  
October 20<sup>th</sup>  
November 17<sup>th</sup>  
December 15<sup>th</sup>

----- Other area Thyroid Cancer Support Groups

ThyCa Baltimore meets the second Saturday of each month

from 10:30 a.m. to 12 noon [Baltimore-MD@thyca.org](mailto:Baltimore-MD@thyca.org)

ThyCa Northern Virginia meets the first Saturday of each month

from 10:30 a.m. to 12 noon [ThyCa\\_Northern\\_VA@thyca.org](mailto:ThyCa_Northern_VA@thyca.org)

## Sample Room Request Letter

Holy Cross Hospital  
Attn.: Mary Smith  
1500 Forest Glen Road  
Silver Spring, MD 20910

Dear Ms. Smith:

As we discussed on the telephone this past Tuesday, I am writing to request space at Holy Cross Hospital for a free, monthly support group for thyroid cancer survivors. This will be the first support group for those diagnosed with this uncommon cancer in this region. Unlike more common cancers, such as breast and prostate, few services for those with thyroid cancer exist. Your support will help change that.

This local support group will be affiliated with the non-for-profit international outreach and education organization, ThyCa: Thyroid Cancer Survivors' Association, Inc. The Association sponsors a mailing list on the Internet, an annual conference and a web page for thyroid cancer survivors. One of its priorities is to nurture local support groups because when one is diagnosed with cancer, nothing can take the place of talking with someone who has walked the same path.

ThyCa group facilitators have found that local groups need the following at their host sites:

- a room that can be reserved for the support group's use once each month for two hours per meeting,
- space for up to 20 people,
- room to place chairs in a circle,
- the same day and time each month for the meeting (I would like to have the meeting on the third Saturday of every month; around 10:30 am. These meetings will run approximately 90 minutes. I would like to schedule the first meeting for Saturday, April 17th if possible),
- the name and telephone number of a contact person at Holy Cross who will be the liaison for our group facilitators.

Once we have confirmed our local site, date and time, we begin publicizing the group's meetings in the local media and on the Internet. It will be listed with the American Cancer Society, National Cancer Institute, and other non-profit information services. Our local support group facilitator is the contact person in our promotional material, but because we list the place, day and time in our promotions, it's

important that someone at your site know about the meetings just in case someone calls. We will also post this information on our web site. To see examples of other local groups, you can go to our web site at <[www.thyca.org](http://www.thyca.org)>.

I look forward to talking with you at your earliest convenience, and am available for any questions you might have.

Thank you for your consideration,

John Smith  
ThyCa Washington, DC Support Group Facilitator  
301-555-1212  
[washington\\_dc@thyca.org](mailto:washington_dc@thyca.org)

## 10. ThyCa Organization

### **ThyCa Board of Directors and Executive Director**

As a nonprofit 501(c)(3) organization, ThyCa has a governing Board of Directors. Our all-volunteer ThyCa Board of Directors provides policy, planning, and oversight guidance for ThyCa's future. Each Board member manages or co-manages one or more ThyCa services or committees that sustain our services. Board members handle many behind-the-scenes administrative and office tasks. We help with outreach, volunteer recruitment, and development. We also support and encourage thyroid cancer survivors and caregivers. The board meets mostly online, sometimes by phone and in person. ThyCa's Board is a working board made up of wonderful people willing to serve.

Each ThyCa Board Member has four roles:

1. Manage or Co-manage one behind-the-scenes team or function (e.g.: membership, toll-free number, publications, conference, and finance).
2. Take part in ongoing online board discussions, consensus building, and decision-making, as well as group phone calls and face-to-face meetings.
3. Tell our friends, family, and others about ThyCa and help recruit and encourage new volunteers.
4. Continue our previous role with ThyCa support services (e.g.: Support Group Facilitator, Person-to-Person Volunteer, Toll Free Number Volunteer, Publications Volunteer, Outreach Volunteer).

We seek people who are happy to give time without external recognition and who feel rewarded by the knowledge that their part in this team effort is making a huge positive difference in the lives of families affected by thyroid cancer. A large part of being on the ThyCa Board involves responding promptly to communications and queries from survivors, family members, other organizations, the media, potential donors, and the public.

Due to ThyCa's growth, ThyCa has had a fulltime Executive Director since September 2007. In collaboration with the Board, our Executive Director is responsible for management to further ThyCa's vision and strategic plan to further grow support services, education, and outreach, especially for underserved populations, as well as to foster research advocacy and alliances.

### **ThyCa Committees**

ThyCa has a number of committees. In addition, the Board of Directors may create special, advisory, and ad hoc committees as the need arises to fulfill ThyCa's mission. These committees are listed alphabetically.

### **Conference/Workshop Committee**

The Conference Committee's primary role is to strengthen and enhance ThyCa's educational services and visibility through organizing and running educational and supportive meetings. These include ThyCa's annual International Thyroid Cancer Survivors' Conference, half-day and one-day regional spring workshops in areas where volunteers step forward to provide onsite leadership, and free local thyroid cancer seminars.

### **E-mail Committee**

The E-Mail Committee's primary role is to respond to electronic queries to ThyCa.

### **Finance Committee**

The Finance Committee is chaired by the Treasurer. The primary role of the Finance Committee is to provide the expertise needed to assure the full Board that ThyCa is in sound financial standing. To perform this role effectively, committee members work as a team with the Executive Director, as well as accountants, the outside audit firm, tax experts, bankers and other financial professionals. Each month, the Finance Committee reports to the Board and Executive Director on ThyCa's financial status and cash balances, other funds, and year-to-date revenues and expenditures.

### **Local Support Group Program Committee**

The Local Support Group Program Committee's primary role is to help Local Support Group Facilitators provide support in a one-to-many environment. The Director of Local Support Groups oversees the Local Support Group Program Committee to ensure developing and existing Local Support Groups are provided (within ThyCa's ability) the guidance and resources needed to support ThyCa's mission within their local area. The committee continually works to improve the overall program, keep local groups active through motivation and training, and create groups in underserved areas.

### **Membership Committee**

The Membership Committee's primary role is to enhance ThyCa's membership. The committee is also responsible for maintaining ThyCa's main database and making sure that members and constituents records are kept up to date.

### **Medical Advisory Council**

The Medical Advisory Council (MAC) advises the Board on medical issues and program.

### **Nominating Committee**

The Nominating Committee plays a key role in ThyCa's success because the people it nominates to become Board member will influence the Board long after their terms expire.

### **Outreach Committee**

The Outreach Committee's primary role is to organize and direct all efforts to enhance ThyCa's visibility, to raise public awareness of thyroid cancer and early detection, to connect patients and caregivers with ThyCa's free support services and educational resources, and to advocate for research fundraising and thyroid cancer research.

### **Publications Committee**

The Publications Committee's primary role is to develop accurate and timely educational, supportive, and event-oriented materials for electronic and print distribution, particularly through ThyCa's web site. The Publications Committee is also a service bureau for other ThyCa committees, providing editing, proofreading, design, and production of internal and externally distributed forms, manuals, toolkits, and other publications.

### **ThyCa Person-to-Person Network (TPPN) Committee**

The TPPN Committee's primary role is to help people in a one-to-one environment. Anyone who has been touched by thyroid cancer (especially those newly diagnosed and/or those dealing with thyroid cancer related issues) can be matched with another thyroid cancer survivor. A volunteer can help by providing emotional and psychological support by sharing experiences, solutions and understanding since they have been through a similar experience. Volunteers do not give medical advice or medical opinions but can provide an empathetic listening ear.

### **Toll-Free Number (TFN) Committee**

The TFN Committee's primary role is to provide peer support in a one-to-one environment by telephone. The TFN committee also assists callers with information about ThyCa's other support and education services. ThyCa maintains a toll-free number that people can call and leave a message on. Volunteers take turns, usually for a week at a time, responding to the messages left, typically within 24 hours. At this time volunteers can respond to messages left in either English or Spanish.

### **Web Site Committee**

The web committee leader (webmaster) and any assistants are charged with maintaining the [www.thyca.org](http://www.thyca.org) web site. This includes updating existing pages and creating new pages and, when necessary, sub webs, as requested by the Publications Committee. The web committee leader also creates all new [thyca.org](http://thyca.org) e-mail address aliases and updates forwarding information for existing addresses. The Support Group sub web requires updating the event calendars and the Yahoo! calendar for all thyroid cancer local support groups.

## **ThyCa Services and Functions**

The number of services has increased substantially since our beginnings in 1995.

### **Public Services**

1. Anaplastic Thyroid Cancer Queries
2. Biotech/Medical Companies; Research Advocacy
3. Community Outreach: Media, Directories, Organizations, Networking, Exhibits, Thyroid Cancer Awareness Month and Year-Round Awareness Campaigns
4. Annual Conference
5. Dinner/Auction Fundraiser
6. E-Mail Support Groups
7. E-Mail Response Team
8. Introduction and Response Letters
9. Local Support Groups

10. Mass e-mailings
11. Medullary Thyroid Cancer Queries
12. Pediatric Thyroid Cancer Queries
13. Membership
14. Physician and other Professional Mailings, Meetings, Exhibits
15. Physician and Other Professional Outreach, Advisors, Associations
16. Publications
17. Research Grants
18. Spanish Translation Project
19. Spirit Items
20. ThyCa Person To Person Network
21. Toll-Free Number
22. Web Site
23. Workshops

### **Organization Services and Administration**

1. Backup, Rapid Responses, Problem-solving, Coordinator Training
2. Condolences
3. Databases
4. Day to Day Operations
5. Discounts/Cost Avoidance/Vendors/In-Kind Donations
6. Financial: Deposits, Payments, Accounts, Donor Acknowledgement, Audit, Tax Forms, Insurance
7. Major Gifts, Grants
8. Policy, Planning
9. Postal Mail (P.O. Boxes)
10. Supplies Storage and Distribution
11. Technology Initiatives
12. Volunteers for Administration and Organization
13. Volunteer Concerns, Emergencies
14. Volunteers for Public Services: Recruitment, Training, Support, Thank You's, Committee Coordinators
15. Volunteer Supplies, Patient Packets, Newsletters

### **Details About Main ThyCa Public Services**

**Our Goal:** To ensure that no one has to be alone as they cope with the unique challenges of thyroid cancer. We accomplish this goal through the services listed below:

- 11 e-mail listservs act as ongoing 24-hour support groups to serve people with each type of thyroid cancer, as well as family members.
- Person-to-Person Network offers one-on-one support worldwide.
- More than 80 active face-to-face support groups in 35 States, Canada, Costa Rica, and Philippines (as of January 2010 – changes frequently)
- [www.thyca.org](http://www.thyca.org) web site receives more than 300,000 visits per month, and sometimes more than 350,000 visits.

- [www.thyca.org](http://www.thyca.org) web site hosts web sites for medullary thyroid cancer, anaplastic thyroid cancer, pediatric thyroid cancer, and both Spanish and Mandarin language versions of the web site are currently being translated.
- Toll-Free Team returns telephone calls, in English and Spanish.
- E-mail [thyca@thyca.org](mailto:thyca@thyca.org) Team replies to thousands of e-mail queries annually.
- FREE Low-Iodine Cookbook, downloadable from our web site. This cookbook now in its 6<sup>th</sup> edition, now has more than 250 recipes from more than 100 contributors. Recipes are also available in Spanish and French.
- Free information packets, mailed worldwide.
- Member Messenger, published quarterly, And ThyCa News Notes is published monthly for anyone impacted by a thyroid cancer diagnosis.
- Spring regional thyroid cancer workshops organized by ThyCa Support Group(s).
- ThyCa sponsors Thyroid Cancer Awareness Month each September, plus year-round awareness campaigns.
- Numerous free downloadable awareness materials in English and Spanish, and numerous educational publications, brochures, and plastic wallet cards available.
- ThyCa Spirit Items such as wristbands, pins, and many more items available on the [www.thyca.org](http://www.thyca.org) web site.
- Annual 3-Day International Thyroid Cancer Survivors' Conference for a nominal fee to cover event costs. Scholarships available by request. So open to all, regardless of ability to pay.
- ThyCa funds clinical thyroid cancer research at medical institutions around the world in collaboration with a grant campaign by the American Thyroid Association (ATA). This peer-reviewed grant process is open to all young investigators worldwide. This research translates basic scientific discoveries into treatments.

### **ThyCa E-Mail Support Groups**

ThyCa sponsors several e-mail support group discussion lists. In these groups, participants share thyroid cancer information and their experiences, strength, and hope, using email messages. Subscribing puts you instantly in touch with large numbers of people worldwide, all dealing with thyroid cancer.

Each list has rules and moderators to ensure that everyone follows the rules. To protect everyone's privacy, one rule is that nobody forwards someone else's e-mail, or shares an address link, without specific written permission in advance from the other person. The groups do not allow commercial messages, fundraising messages, and other topics not in keeping with a support group.

The lists are free and simple to join. ThyCa operates them through Yahoo! Groups. You have a choice of whether to receive all messages individually, whether to receive just one e-mail each day (with all the day's messages), or whether to receive no e-mails and instead to read messages, as you choose, on the group's web site.

## 11. ThyCa-Provided Materials and Forms

The materials listed below are available from ThyCa:

### Organizational Forms:

- Support Group Participant List
- Sign-in Sheet
- Arrow Signs

### Materials for Distribution:

- List of all ThyCa downloadable flyers and booklets
- Thyroid Cancer Resource List
- ThyCa Support Group Flyer
- Low Iodine Diet Cookbook Flyer – in English and Spanish
- Low Iodine Diet Guidelines – in English and Spanish
- Know Your Pills – in English and Spanish
- Membership Form
- Volunteering Form
- Spirit Merchandise Order Form

- Catherine Bell Thyroid Cancer Awareness Brochures
- “Do You Have Thyroid Cancer” Brochures
- Fine Needle Aspiration Booklets – in English and Spanish
- Low Iodine Diet Cookbook – in English, Spanish, and French
- Wallet cards detailing ThyCa services

- American Thyroid Association Management Guidelines for Patients with Thyroid Nodules and Differentiated Thyroid Cancer
- American Thyroid Association Medullary Thyroid Cancer: First Comprehensive Guidelines for Managing Medullary Thyroid Carcinoma