

# ThyCa Journeys

A free publication of ThyCa: Thyroid Cancer Survivors' Association, Inc. <[www.thyca.org](http://www.thyca.org)>  
Support, education, and communication for thyroid cancer survivors and families.

Summer 2004

## Thank You, Catherine Bell! New Thyroid Cancer Awareness Brochure Distributed Nationwide

ThyCa is excited to announce that physicians across the United States have requested large quantities of our new free Thyroid Cancer Awareness Brochure to give to their patients. The brochure features actress Catherine Bell, co-star of the hit CBS TV series JAG, and thyroid cancer survivor.

This free brochure presents information about thyroid cancer types, symptoms to discuss with your physician, as well as ThyCa's free support and education services available worldwide.

In addition, Catherine Bell shares her own story and highlights the importance of learning about thyroid cancer and the resources available to those diagnosed with the disease.

We're proud of this new brochure and grateful to Catherine for her terrific support of our outreach and awareness efforts. This brochure gives important support to ThyCa's ongoing efforts to raise awareness of the need for early detection, treatment and follow-up of thyroid cancer, and to provide support for those whose lives have been touched by thyroid cancer.

Free copies of the brochure are available by sending an e-mail to [thyca@thyca.org](mailto:thyca@thyca.org), faxing to 630-604-6078, or writing to ThyCa Brochures, PO Box 1545, New York, NY 10159-1545.

## Drs. Haugen and Ringel New Members of our Medical Advisory Council

We're pleased to announce that Bryan R. Haugen M.D. and Matthew D. Ringel, M.D. have become members of ThyCa's Medical Advisory Council.

Dr. Haugen is an endocrinologist and thyroid cancer specialist at the University of Colorado Health Sciences Center in Denver, Colorado.

—cont. on page 2

### Inside This Issue

7th ThyCa Conference October 22-24 near Chicago.....	2
Awareness Ribbon Pin.....	3
New Book.....	5
ThyCa Awards Research Grant.....	5
plus Thyrogen and Levothyroxine in the News, Benefit Dinner/ Auction, Airport Story, ThyCa's Members, Letter from Germany, and more.....	6-10

## Letter from the Editor

Dear Readers,

Welcome to the Summer 2004 edition of *Journeys*! Usually, as I put this newsletter together, the first thing I write is the editor's note. This time, I've been struggling to come up with a topic.

It has been five years since my initial thyroid cancer diagnosis, and almost 2 since my blood tests started coming back clean. I was in my early 20s then and my late 20s now. I no longer notice, when I look at an old, pre-surgery photo, the absence of a scar on my neck.

In a couple of weeks, I'll be moving to a new home, where my bedroom will not be the one in which I lay awake with fear before my surgeries and scans. I actually met my thyroid specialist for a check-up last month and didn't feel violently ill beforehand. I have a different job than I had when I was told I had thyroid cancer while sitting at my office desk. I no longer think other people have to know about my cancer to know the real me.

Thyroid cancer is not the first thing I think of every day, before thinking about it 200 more times during the day. I've more or less stopped resenting the fact that I have to rely on a pill each morning to ensure that I'll have enough energy to get out of bed next week. (Though I still can't watch an episode of Gilligan's Island without thinking that if I were somehow shipwrecked without my thyroid medication, I'd be in serious trouble.)

It's taken me five years to get here, and I honestly didn't expect I ever would. I just assumed thyroid cancer would always be the **THE THING** in my life. And so, if the cost of all this emotional healing is a little writer's block, it's a trade off I'll make happily.

I hope you enjoy this edition of *Journeys* and have a relaxing, happy and healthy summer.

Be well,  
Barbara Weinstein, Editor

Copyright (c) 2004 ThyCa: Thyroid Cancer Survivors' Association, Inc. <[www.thyca.org](http://www.thyca.org)>. We encourage you to send this newsletter to your family and friends. For permission to reprint in another electronic or print publication, please contact ThyCa at [thyca@thyca.org](mailto:thyca@thyca.org).

## Come to the 7th ThyCa Conference October 22-24, 2004, Chicago, Illinois

The 7th International Thyroid Cancer Survivors' Conference is fast approaching! Registration for the October 22-24 conference is now available on-line. Reserve your rooms at the conference's hotel, the Hyatt Deerfield Hotel in Deerfield, Illinois, in the suburban area north of Chicago.

This unique educational and supportive event will feature more than 60 presentations, workshops, and roundtables led by leading physicians and other specialists. The conference is designed for everyone whose life has been touched by thyroid cancer— people being tested or newly diagnosed with each type of thyroid cancer; long-term survivors; people dealing with advanced disease; caregivers; and friends.

This weekend offers a wonderful opportunity to learn from thyroid cancer specialist physicians and to meet other survivors and caregivers. During last year's conference, thyroid cancer survivors, family members, and friends came from 32 states, Canada, and the United Kingdom.

Register soon! For more information, and to register, visit the ThyCa web site at [www.thyca.org](http://www.thyca.org). If you have any questions, please e-mail: [conference@thyca.org](mailto:conference@thyca.org).

### *Special Welcome to Chicago*

ThyCa Chicago would like to welcome you to Chicago! The windy city is a great place to meet old and new friends. Please let us know if we can assist you in any way before and during your stay. Enjoy the conference and please introduce yourself!

*Allison Hoffman and Jeni Ton*

ThyCa Chicago Support Group Facilitators  
[Chicago\\_IL@thyca.org](mailto:Chicago_IL@thyca.org)

### **Medullary Dinner in Chicago**

An annual tradition at the ThyCa conference is the special dinner for medullary thyroid cancer survivors and families. The dinner takes place the Saturday evening of the conference. If you're interested, please e-mail to [conference@thyca.org](mailto:conference@thyca.org) for details.

### *Drs. Haugen and Ringel—*

*cont. from p. 1*

He is Associate Professor of Medicine and Pathology and Director of the Thyroid Tumor Center. He has been studying potential mechanisms involved in thyroid neoplasia and cancer, including the roles of telomerase and the retinoic acid receptors, and is interested in newer therapies for thyroid cancer and metabolic consequences of subclinical hypothyroidism.

Dr. Haugen also is a member of the Executive Council of the American Thyroid Association. His presentation at ThyCa's 5th International Thyroid Cancer Survivors' Conference in Los Angeles in 2002 focused on the management of advanced thyroid cancer.

Dr. Ringel is an endocrinologist, thyroid cancer specialist, and thyroid cancer researcher at the Ohio State University Comprehensive Cancer Center—James Cancer Hospital and Solove Research Institute. He also is Associate Professor at the Ohio State University College of Medicine and Public Health.

Dr. Ringel is a member of the Research Committee of the American Thyroid Association and chairs its web site advisory group. He has spoken at ThyCa's thyroid cancer survivors' conferences about future trends in thyroid cancer care. He is also a chapter author for the recently published book *Thyroid Cancer: A Guide for Patients* (Douglas Van Nostrand, M.D., Gary Bloom, and Leonard Wartofsky, M.D., editors. See article on page 5).

The ThyCa Medical Advisory Council provides valuable counsel and supports ThyCa's goals in education, treatment, and research.

### *Thank You, Survey Participants*

ThyCa thanks the more than 2,000 thyroid cancer survivors who completed the first-ever online Thyroid Cancer Patient Experience Survey. The data analysis and report preparation are now under way. The results will be reviewed and analyzed by thyroid cancer specialist physicians and the findings will be reported on ThyCa's web site.

The survey is sponsored by ThyCa: Thyroid Cancer Survivors' Association, Inc. The questionnaire was developed by ThyCa volunteers, with input from thyroid cancer specialist physicians. Survey funding came from the Advisory Board Foundation, Genzyme Therapeutics, and ThyCa: Thyroid Cancer Survivors' Association, Inc.

## **New! Awareness Ribbon Pin Now Available**

ThyCa is excited to announce the new Thyroid Cancer Awareness Ribbon Pin! It's now available through the ThyCa web site.

This beautiful three-colored pin features two shades of blue, plus pink. It arrives just in time for Thyroid Cancer Awareness Week in September. We also welcome everyone's awareness efforts throughout the year.

All proceeds will benefit ThyCa's free support services and thyroid cancer research. You'll find a photo and the order form in our web site's ThyCa Merchandise section <[http://www.thyca.org/Spirit\\_Items\\_021304.htm](http://www.thyca.org/Spirit_Items_021304.htm)>.

## **ThyCa News Nuggets**

**Congratulations, Jan!** We're proud to announce that Jan Scheuerman of Florida has been named ThyCa Board Member Emeritus. Jan is one of ThyCa's co-founders. She also is the founder and co-facilitator of ThyCa's Suncoast support group in Fort Myers, Florida. She also volunteers behind the scenes in many ways for ThyCa, giving support and encouragement to newcomers, and providing ideas and supporting and assisting at our conferences. Congratulations and thank you, Jan!

**New Support Groups.** ThyCa's newest local support groups are up and running, bringing more groups to different parts of the United States.

Idaho's first support group, ThyCa Idaho Falls, meets from 10:30 a.m. to noon on the 3rd Saturday of each month at the Idaho Falls Cancer Center. For more information, contact Alyssa Dodd by e-mail at [idahofalls-id@thyca.org](mailto:idahofalls-id@thyca.org) or by phoning 208-589-4756.

In southwest Virginia, ThyCa Roanoke meets from 10:30-12 noon on the 1st Saturday of each month at the Lewis-Gale Medical Center Oncology Center in Salem, VA. For more information, contact Patrick Alberti at 434-258-7717 or e-mail: [Roanoke-VA@thyca.org](mailto:Roanoke-VA@thyca.org). This group is Virginia's second ThyCa support group.

We're also excited to announce the first support groups in two more states. South Carolina's first support group will meet in Spartanburg starting in August, with Dr. Donna Smith the facilitator. Louisiana's first support group, ThyCa New Orleans, will start meeting in September. Kathy Bailey is the facilitator. More details are on our web site. Our web site's ThyCa Support Groups page <<http://www.thyca.org/support.htm>> has details about all our local support groups.

**Help for Starting a Group.** If you'd like information about starting a new thyroid cancer support group in your area, contact Sara Gorrell Brenner, ThyCa Support Groups Coordinator and ThyCa Northern Virginia Co-Facilitator, at [support\\_coord@thyca.org](mailto:support_coord@thyca.org).

**Physicians' Presentations.** Thank you very much to Kenneth D. Burman, M.D., Director of Endocrinology, Washington Hospital Center, and ThyCa Medical Advisor, for your presentation and question and answer session at ThyCa Baltimore, Maryland, Support Group Meeting on June 12.

Our thanks also to Stephanie L. Lee, M.D., Ph.D., Associate Professor of Medicine and Director of the Endocrine Clinics at Boston Medical Center, who spoke about iodine in the American diet and its implications for thyroid cancer, at the ThyCa Boston, Massachusetts, Support Group Meeting on July 17.

**Cheri and the ATC Group.** Cheri Wallace Lindle, ThyCa volunteer from Oklahoma, has been helping ThyCa in many ways. When her father, Bob Collins, was diagnosed with anaplastic thyroid cancer (ATC) in 1997, Cheri started reaching out over the Internet. The ATC e-mail support group that Cheri initiated is now one of ThyCa's eight e-mail support groups.

Cheri also represented ThyCa in June at the meeting of the American Society of Clinical Oncology in New Orleans, Louisiana. Most recently, Cheri has joined ThyCa's Publications Committee. Our Membership Messenger published the story of Cheri and her father. You'll find it in the Newsletters section of our web site. Thank you, Cheri.

**Survivor's Story.** Kevin Wychopen, a California thyroid cancer survivor, kept a journal of his experience and called it "Adventures in Thyroidland." With insight and humor, Kevin shared his experiences and has generously agreed to have excerpts published in our *Membership Messenger* newsletter and in full on our web site in the Newsletters section.

**Newspaper Article.** Tina Anders, ThyCa Denver Support Group Co-Facilitator, was featured with her children in the lead article in a June 2004 issue of *Jeffco News*, a newspaper serving northern Colorado. The article described the experiences of Tina and her children with familial medullary thyroid cancer and her involvement in offering support to other thyroid cancer survivors and fundraising for research.

## ThyCa News Nuggets— *cont. from p. 3*

**ATA Alliance Forums.** ThyCa is part of the American Thyroid Association Alliance for Thyroid Patient Education. In April in Boston, Massachusetts, and June in New Orleans, Louisiana, the ATA Alliance sponsored a free public forum on all types of thyroid diseases, including thyroid cancer. Representing ThyCa and organizing our displays at these events were Sherri Eccleston, ThyCa Rhode Island Support Group Facilitator, and Leah Guljord, ThyCa Assistant Board Chair, ThyCa Spacecoast Support Group Facilitator, and Low-Iodine Cookbook Editor.

**Displays.** ThyCa volunteers around the country displayed and distributed our materials at many cancer survivorship events this spring.

Jan Scheurman, ThyCa Suncoast Support Group Facilitator, who organized two displays in Florida. Jaime Toth, ThyCa Southern Connecticut Support Group Facilitator, organized a ThyCa display at a cancer awareness event in Vermont.

Sandy Wagnon managed ThyCa's display at the Cure Magazine forum in Texas. Cherry Wunderlich handled displays at seminars in Washington, DC, one on coping with fatigue and the other on employment issues for cancer survivors, co-sponsored by several cancer survivorship organizations.

Other volunteers distributed materials through their Mom's Club, a yard sale, and community organizations. Thank you to everyone for your help.

**Slide Show.** Evelyn Gross, ThyCa Board Member and facilitator of the ThyCa Philadelphia Support Group, has created an informative slide show to introduce physicians to ThyCa's support services, web site, special events, and other resources. The PDF version of the slide show is linked from the Home Page of ThyCa's web site.

**Medical Meetings.** ThyCa was represented at several physicians' meetings this spring. These included the annual meetings of the American Association of Clinical Endocrinologists, American Society of Clinical Oncology, The Endocrine Society, and Society of Nuclear Medicine, and the 9th International Workshop on Multiple Endocrine Neoplasia.

**Growing E-Mail Groups.** More than 3,000 people now take part in ThyCa's e-mail support groups. Our largest e-mail support group, the "Thyca" group (primarily for papillary and follicular thyroid cancer) has grown to more than 1,900 participants. Two ThyCa volunteers, Kristie R. Creamer and Karen Ferguson, are developing a new group. Our web site has details about all our on-line support groups.

## *The Love, Loss, and Legacy E-Mail Support Group*

Our newest e-mail support group comes from the love and caring of a devoted family. Many of us had the privilege of meeting David and Pattie Scott of Colorado at our conference in Los Angeles in 2002. Dave had been diagnosed with anaplastic thyroid cancer in March of that year.

Pattie devoted her energy towards learning and researching thyroid cancer. She became her husband's primary caregiver and advocate, until his passing on February 28, 2003.

Pattie has continued her involvement with ThyCa. She supports and helps survivors, their caregivers, and their families. At our 2003 conference in Houston, she led a group discussion on caregiving and coping before, during, and after loss.

From this experience, her volunteering, and her professional training and experience as a nurse, she has developed our newest support group, the Love, Loss, & Legacy Group.

The purpose of the group is to provide a safe haven for caregivers, families, and friends to express their feelings, seek information and receive support while coping with difficult situations.

The group is also meant to assist persons with questions and concerns regarding end-of-life issues. It also encourages the participation of thyroid cancer patients coping with end-of-life issues. This is also a place where persons going through the bereavement period can find the support needed to promote healing.

Themes may include the following: financial and legal concerns, palliative care, hospice resources, communication about impending death, funeral arrangements, grief resources, feelings after a loss, helping children cope, support resources, developing new coping skills. All communications are confidential and stay within the group.

If you know of someone who might benefit from participating in this group, please let them know about it. The details and instructions for joining are on the ThyCa web site [www.thyca.org](http://www.thyca.org) in the ThyCa Support Groups section, on the E-Mail Support Groups Page.



## **New Book: *Thyroid Cancer: A Guide for Patients***

The new book titled *Thyroid Cancer: A Guide for Patients* has just been published by Keystone Press.

The editors are Douglas Van Nostrand, M.D., Director of Nuclear Medicine at the Washington Hospital Center; Gary Bloom, ThyCa Co-Founder and Board Chair; and Leonard Wartofsky, M.D., Endocrinologist, Director of Medicine at the Washington Hospital Center, Professor of Medicine at Georgetown University and the Uniformed Services University of the Health Sciences, and former president of the American Thyroid Association.

Ernest Mazzaferri, M.D., Emeritus Professor and Chair of Medicine, Ohio State University and Adjunct Professor of Medicine, University of Florida, wrote the Foreword. The book has 336 pages, including charts and illustrations.

The 28 contributing authors include 18 physicians, among them ThyCa medical advisors Kenneth D. Burman, M.D., Endocrinologist, Washington Hospital Center; Matthew D. Ringel, M.D., Endocrinologist, Ohio State University; and Yolanda C. Oertel, M.D., Pathologist, Washington Hospital Center; as well as several other physicians who have spoken at ThyCa conferences and workshops. The authors also include other specialists, thyroid cancer survivors, and a caregiver.

The book is available on [www.amazon.com](http://www.amazon.com) and also through ThyCa, mailed by ThyCa volunteers. All proceeds above publisher's cost, from books purchased through ThyCa, will go to support ThyCa's free support services and thyroid cancer and medullary thyroid cancer research funds.

Details are on the ThyCa web site, linked on the right side of the Home Page <[www.thyca.org](http://www.thyca.org)>.

## **Thank You, Regional Workshop Volunteers**

ThyCa continues to expand its roster of workshops. Watch our web site for details on the upcoming workshop in Denver, Colorado. ThyCa is cooperating with the University of Colorado Health Sciences Center in presenting this free program on thyroid cancer.

This spring, ThyCa volunteers in two other regions organized two free day-long workshops. In April, the DC Capital Area ThyCa Support Groups hosted their 3rd annual workshop at Holy Cross Hospital in Silver Spring, Maryland. More than 90 people participated.

Our thanks to our speakers, Loukas Gourgiotis, M.D., Endocrinologist, National Institutes of Health, Bethesda, MD; Jacqueline Jonklass, M.D., Endocrinologist, Georgetown University Medical Center; Stanley Knoll, M.D., Clinical Professor of Surgery, George Washington University Medical Center and Georgetown University Medical Center; and Kathleen A. Prendergast, M.D., Endocrinologist, Washington Hospital Center.

In June, the New England ThyCa Support Groups hosted their 4th annual workshop at the University of Massachusetts Medical Center in Worcester, Massachusetts. Special thanks to the speakers, including Alan Farwell, M.D., Endocrinologist, Staff Physician, UMass Memorial Health Center, and Faculty, University of Massachusetts Medical School; James Warshaw, M.D., Endocrinologist, Private Practice, Taunton, MA, and Courtesy Staff Physician, Rhode Island Hospital; Charles Emerson, M.D., Endocrinologist; Giles Whalen, M.D., Thyroid Surgeon; and Anne Larkin, M.D., Thyroid Surgeon.

Look for more information about upcoming support group guest speakers and special events on the ThyCa website, [www.thyca.org](http://www.thyca.org)

## ThyCa Announces 2004 Grant Award for Thyroid Cancer Research

ThyCa: Thyroid Cancer Survivors' Association, Inc. is pleased to announce the awarding of our second grant for thyroid cancer research.

The grant recipient is Sareh Parangi, M.D., Assistant Professor of Surgery at Harvard Medical School, Boston, Mass. Dr. Parangi's project is titled "Antiangiogenic Therapy of Thyroid Cancer." Her project will focus on growth of blood vessels (angiogenesis) to tumors, using a mouse model that closely resembles human thyroid cancer, and on thrombospondin, a natural inhibitor of angiogenesis that appears to be important in thyroid disease.

The grant review and selection process was conducted by the scientific review panel of the American Thyroid Association (ATA), the professional association of clinicians and researchers involved in thyroid diseases. The award was based on a review of the scientific merits of the grant proposals, independent of hospital or institutional affiliation. The grant fundraising was conducted by the volunteers of ThyCa: Thyroid Cancer Survivors' Association, Inc. through our campaign for thyroid cancer research.

Dr. Parangi earned her M.D. degree at the Columbia University College of Physicians and Surgeons after graduating from Barnard College, magna cum laude and Phi Beta Kappa. She did her surgical training in endocrine surgery at the University of California, San Francisco (UCSF) with Dr. Orlo Clark. She was Chief Resident in Surgery at UCSF in 1997-98. She joined the staff of Beth Israel Deaconess Medical Center and Harvard Medical School in 1998.

Dr. Parangi's previous research has focused on angiogenesis in endocrine and non-endocrine pancreatic tumors and the molecular effects of thrombospondin on endothelial apoptosis. The project will examine whether angiogenesis inhibitors can be used singly and in combination to reduce tumor burden and whether novel delivery mechanisms can increase the efficacy of antiangiogenic agents. Associated with Dr. Parangi in the ThyCa-funded research will be Xuefeng Zhang, M.D., Ph.D., Postdoctoral Fellow at Harvard Medical School.

Gary Bloom, ThyCa Board Chair, said, "We thank everyone involved in this important effort. We greatly appreciate the American Thyroid Association's support and involvement in the grant review and selection, as well as ATA's support for patient and family education and its members' commitment to the care of thyroid cancer patients."

"We are proud of this new milestone in our support for research aimed at achieving our dream of a cure for all thyroid cancer. We thank all the wonderful volunteers and donors throughout the country who have supported these important efforts," said Joni Eskenazi, ThyCa Board Member and Fundraising Chair.

### Letter from Germany

*(Editor's Note: From an e-mail to ThyCa on June 25, 2004. The writer presented a research poster on the RET protooncogene (related to medullary thyroid cancer) at the 9th International Workshop on Multiple Endocrine Neoplasia (MEN 2004) in Bethesda, Maryland, on June 20-22, 2004. Attendees and presenters included physicians and researchers from 19 countries. Included were ThyCa medical advisors Drs. Burman, Gagel, Moley, Ringel, and Skarulis, as well as Dr. Moley's longtime research nurse Mary Debenedetti, R.N., B.S.N.. ThyCa had materials on display at this meeting.)*

"It was a pleasure meeting you at the MEN meeting in Bethesda. Please find enclosed as a word document the abstract I told you about..."

"I also would be interested in sharing with others my personal experiences as a patient and as a surgeon treating patients with thyroid cancer. I was already working as a MD when I got ill in 1992 and substantially determined my own treatment. In total I had 5 major operations with complications as well as Radioiodine treatments, etc. Moreover I have given talks about management of thyroid cancer in Europe and the US...."

"So if you should be interested in any participation from my side ...as a surgeon with endocrine expertise or my experiences as a patient, please let me know. I would be only too happy to share my knowledge and experiences."

Sincerely yours,  
Mario Colombo-Benkmann, M.D.  
Assistant Professor of Surgery  
University of Münster

### An Open Invitation from ThyCa

ThyCa invites thyroid cancer survivors, families, and friends to tell your friends and relatives about our free year-round support services and publications, including our award-winning educational web site, as well as about our workshops and conference.

If you'd like to help us sustain and strengthen our free support services and educational resources, we invite you to visit our web site to find out how to help through membership, donations, and volunteering.

Thank you very much for your support.

# Rally for Research 2004



As part of ThyCa's ongoing efforts to raise funds to find a cure for all thyroid cancer, ThyCa's 2004 Research Fundraising Campaign is under way.

The 2004 campaign kicked off on May 16th, uniting survivors, family, friends, neighbors and loved ones in an international effort to raise funds to combat thyroid cancer. Events initiated and organized by survivors, families, and friends this year and in past years have included car washes, walks, marathon races, bicycle events, bake sales, golf tournaments, bridge, card and board games, as well as outdoor games and sporting events.

If you've been unable to host or participate in an event, it's never too late to make a difference! Choose any day and make it special by declaring it a Thyroid Cancer "Rally for Research" day. Plan a community-wide effort to raise funds for thyroid cancer research. Let ThyCa know about your program so we can announce it on our web site and invite all our site's visitors to sponsor you!

## *Dinner/Auction To Support Research*

Whether or not you're able to attend ThyCa's 2004 Conference, we invite you to support our 3rd Annual Dinner/Auction Fundraiser for Thyroid Cancer Research. Julie Robinson, ThyCa volunteer (Missouri) is this year's Dinner/Auction Coordinator. She and many other volunteers are busy organizing this evening, to be held at the Hyatt Deerfield Hotel in Deerfield, Illinois, on Friday evening, October 22. For details on this event and how you can support it, visit the ThyCa web site.

## Thyrogen and Levothyroxine in the News

**Thyrogen Study.** Research presented by Paul Ladenson, M.D., at The Endocrine Society Annual Meeting in June compared the use of recombinant TSH (Thyrogen, made by Genzyme) and the use of withdrawal from thyroid hormone to raise TSH for thyroid remnant ablation following surgery for differentiated thyroid cancer. The analysis concluded that the two methods produced similar results. Currently, the Food and Drug Administration (FDA) has approved Thyrogen for use only in radioiodine scans, and it is sometimes used for ablation as well. Dr. Ladenson is an Endocrinologist, Director of Endocrinology at The Johns Hopkins Medical Institutions, President-Elect of the American Thyroid Association, and ThyCa Medical Advisor.

**Levothyroxine.** In other recent news, as reported on the American Thyroid Association web site, [www.thyroid.org](http://www.thyroid.org), the Food and Drug Administration (FDA) has approved generic substitutes for levothyroxine products. The FDA decision allows a pharmacist to substitute one drug for another without physician approval.

The ATA web site notes, "In a June 24, 2004, statement, the American Thyroid Association (ATA), The Endocrine Society (TES), and the American Association of Clinical Endocrinologists (AACE) outlined their concerns about this decision," including concerns for patients with thyroid cancer.

Their statement continued, "As a result of the FDA decision, the ATA, TES, and AACE advise physicians caring for patients on levothyroxine therapy to —

1. Alert their patients that their levothyroxine preparation may be switched at the pharmacy,
2. Encourage their patients to ask to remain on their current levothyroxine preparation, and
3. Make sure their patients understand that if they receive a new levothyroxine preparation that they will need to be retested with a serum TSH to determine if they need dose retitration."

The ATA Alliance for Thyroid Patient Education sent a media announcement on this topic, which is also covered in the new "Know Your Pills" page on the ThyCa web site.

---

## Airport Story

This spring, a *Wall Street Journal* writer contacted ThyCa for information to be used in an article about radiation detectors, found in airports and elsewhere, and reports of their being triggered by patients who have recently received radioactive iodine.

Lora, a California thyroid cancer survivor, told us that this had happened to her twice in Los Angeles International Airport, after receiving treatment doses of radioactive iodine. At the time of the first incident, 15 days had passed since her radioactive iodine treatment. She triggered every one of the alarms in Customs.

Lora's second incident came 21 days after she had received 200 millicuries of radioiodine. This time, traces of her radioactive iodine triggered one radiation detector.

To help patients who might encounter similar situations, the American Thyroid Association has published guidelines and a suggested letter for patients to obtain from their physician if they plan to travel after receiving radioiodine.

These materials are available on the American Thyroid Association web site. They are also linked from the ThyCa web site Links section.

## Have You Checked Out the ThyCa Web Site Lately?

Our web site <[www.thyca.org](http://www.thyca.org)> is chock full of information for newcomers, long-term survivors, caregivers, and family members.

Most recently, we've added a new handout titled "Know Your Pills" to the Newly Diagnosed section, and we've added and grouped the materials in the same section, as well as adding more details about our 2004 conference.

In addition, our expanded *Low Iodine Cookbook* is available free for downloading and provides recipes for even the most hypothyroid chef. Our Newsletters section has added more articles from survivors and a caregiver our Membership Messenger.

Information about testing, thyroid cancer variants and clinical trials will assist any patient looking to improve his or her knowledge and impress the physicians. The humor section provides jokes and songs to bring smiles. Log on now to see what you've been missing and check back regularly for important updates about our conference and more.



## ThyCa's Members

ThyCa's members live in 44 states, the District of Columbia, Canada, Italy, Nigeria, Korea, and New Zealand.

Our oldest member was born in 1917. Our youngest member was born in 1990.



## *Become a ThyCa Member*



Dear Friend of ThyCa,

Maybe you belong to one of our listservs. Maybe you attend one of our local support groups. Maybe you have attended one of our conferences. Or maybe you have called our Toll Free Number, have been matched with one of our volunteers through our Person to Person Network, researched thyroid cancer on our award winning website, and downloaded our free Low Iodine Diet Cookbook. ThyCa offers all of these services, as well as this newsletter, free of charge.

In addition to our free support services, ThyCa serves as a link between survivors and other cancer and endocrine organizations, develops and distributes publications, and participates at endocrine meetings, cancer education programs, and community health meetings.

While all of our support services are free of charge, ThyCa needs your help to continue and grow. This is how your membership helps us continue helping you and help others who may find themselves on the same journey. Membership dues cover ThyCa's operating expenses for outreach, education, peer support, web site, listservs, local support groups, annual conference, regional workshops, physician contacts, Person to Person Network, toll free number, and much more.

Research donations are welcome, needed and appreciated. However, ThyCa does not use research funds to fund its day-to-day operation. We depend on membership dues and other donations for these expenses. These expenses do not include salaries, as ThyCa is an all-volunteer organization.

Available only to members is the "Membership Messenger" newsletter. It is a friendly publication that has included interviews with those who help make ThyCa run, pictures from our conferences, some new low iodine recipes. It is whatever the membership wants it to be.

All members of ThyCa also receive discounted registration fees for our conferences.

Please help us continue to support you and everyone else that has been diagnosed with thyroid cancer.

Membership in ThyCa is only \$25 a year, \$45 for two years, or \$225 for a lifetime membership.

For your convenience, you can become a member on our web site by going to [www.thyca.org](http://www.thyca.org) and click on Membership. You can join online, or print out and mail the membership form. Do it today!!!

Sincerely,

ThyCa Inc., Membership Committee

*Karen Ferguson, Evelyn Gross, Leah Guljord, and Mary Rose Weckerle*

## *Help Spread the Word*

### Thyroid Cancer Awareness Week — September 13-19, 2004

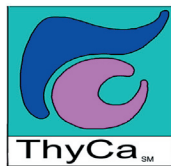
*And All of September is Thyroid Cancer Awareness Month!*

Thyroid Cancer Awareness Week and Month are sponsored by ThyCa: Thyroid Cancer Survivors' Association, Inc. <[www.thyca.org](http://www.thyca.org)>

Please help spread the word. Tell your friends and relatives about thyroid cancer—and the importance of early detection, treatment, and lifelong follow-up.

Tell them also about the free support services and education that are available from ThyCa. You're welcome to share the free educational materials from our web site. Or contact ThyCa. We'll be happy to send more materials to you.

Thank you very much for your support!



## **More About this Newsletter and ThyCa**

This free newsletter is posted on our web site and distributed by e-mail. The articles in this newsletter represent the opinions of their authors and are not official positions of ThyCa: Thyroid Cancer Survivors' Association, Inc. The articles by laypeople do not offer medical advice, as the authors are not doctors and have no medical training. If you have medical questions, please consult with your physician.

ThyCa: Thyroid Cancer Survivors' Association, Inc. <[www.thyca.org](http://www.thyca.org)> is an all-volunteer national nonprofit 501(c)(3) service organization advised by nationally recognized thyroid cancer specialists and dedicated to support, education, and communication for thyroid cancer survivors, their families, and friends.

Throughout the year ThyCa offers free services and resources. These include education about thyroid cancer through our award-winning web site, our low-iodine cookbook downloadable from the web site, eight e-mail support groups, local support groups coast to coast, our person-to-person network for one-to-one support, newsletters, and our survivors' toll-free telephone number.

We welcome new volunteers and members at any time.

*Special thanks to everyone who contribute to ThyCa Journeys. The following volunteers helped plan, edit, proofread, and design this issue: Barbara Weinstein, Editor, and Gary Bloom, M. L. Sprung, Ed Walker, Jo Walker, and Cherry Wunderlich.*

Please share this free newsletter, as well as our other other free awareness, education, and support materials with your family and friends.