



ThyCa Journeys

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

Summer 2003

ThyCa's Sixth International Conference in Houston October 24-26, 2003

ThyCa's annual conference is fast approaching and more than 50 confirmed speakers are on the schedule! Doctors, nurses, mental health care professionals, a pharmacist, attorneys, other specialists, survivors, and caregivers will be converging on the Wyndham Greenspoint Hotel, 12400 Greenspoint Drive in Houston, Texas for a weekend of education, support, and fun October 24-26.

The more than 60 conference sessions include those of interest to the newly diagnosed, those diagnosed in the last few years, long-term survivors, and caregivers. Among the scheduled topics are: If You're New to Thyroid Cancer: Things You Need To Know; Thyroid Cancer Diagnosis: Fine Needle Aspiration and Tissue Analysis after Surgery; Medullary Thyroid Cancer Care and Research; Ask about Nuclear Medicine; Meditation Techniques; Caregivers' Issues; Ask a Doctor about Papillary and Follicular Thyroid Cancer; Update on PET Scans and Other Imaging Techniques; Ask a Surgeon about Thyroid Surgery and Voice Issues; Future Treatment Strategies for Thyroid Cancer;

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R. Michael Tuttle, M.D., New Member of our Medical Advisory Council

R. Michael Tuttle, M.D., Endocrinologist at Memorial Sloan-Kettering Cancer Center in New York, NY, has become a member of ThyCa's Medical Advisory Council. Thank you and welcome, Dr. Tuttle!

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Letter from the Editor

Dear Readers,

Welcome to the Summer 2003 issue of Journeys. I hope you enjoy reading about some of the recent and upcoming activities in which ThyCa and our members are involved. Best of all is our fast-approaching annual conference, to be held in Houston, Texas, October 24-26, 2003.

The conference is a great opportunity to learn more about thyroid cancer and also enjoy the supportive environment that comes from the gathering of hundreds of participants who share the common bond of thyroid cancer.

The balance between providing support and providing information that can be scary and overwhelming is not easy to achieve. Yet finding that balance is why ThyCa exists.

My first encounter with ThyCa was at the 2000 conference in Maryland. At the time, I had spent a year struggling to come to terms with my cancer diagnosis. I trusted my doctors, but I had no real understanding of the disease, the differences between the various prescribed scans, or how particular treatments worked.

At the same time, although I shared some of my anxieties with supportive family and friends, I usually did so with a sense of guilt for burdening them with my troubles. Yet at the ThyCa conference, everyone in the room wanted to talk about thyroid cancer. I spent three days having a terrific time talking about the worst thing that had ever happened to me.

As I reveled in the support that came from simply being among scores of people who understood my situation, I learned about my illness. The facts were not always comforting. After all, cancer is cancer. But knowing the biology of the disease, why my doctors had chosen a particular treatment, and understanding the protocols I could expect in the future made me feel more confident.

Why was the experience so positive for me? Precisely because it provided the balance of information and support that I had been missing. That balance is different for everyone. But through its conferences, support groups, workshops, and web site, ThyCa tries to help all thyroid cancer patients, survivors and caregivers find the balance that is right for them.

And I hope that in this issue of Journeys, you find for yourself a little of that balance as well.

Be well,
Barbara Weinstein, Editor

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Conference — cont. from page 1

Radiation Safety Tips and Suggestions for Use at Home after RAI; Ask a Pharmacist about Medications; When a Child or Adolescent Has Thyroid Cancer; Health Insurance Issues; Anaplastic Thyroid Cancer Research; Legal Issues Related to Employment, Workplace, Disability; Thyrogen Update; and Thyroglobulin Monitoring.

Our Cancer Research Frontiers presentation will focus on immunotherapy, a newer research area that has already shown promise for advanced melanoma and is considered relevant for thyroid cancer as well. An updated list of scheduled topics will soon be available on the ThyCa web site.

As past conference participants and attendees know, the ThyCa annual international conference is an unparalleled opportunity to learn the latest information from experts in the field of diagnosis, treatment, and follow-up care for all types and variants of thyroid cancer. The weekend is also a unique chance to meet others whose lives have been touched by thyroid cancer and to share in the supportive atmosphere.

The conference has a nominal registration fee, and scholarships are available to anyone unable to afford the fee. There also are early-bird and member discounts. The registration fees help cover our expenses for printing, postage, audiovisuals, etc. The conference tries to break even; it's not a fundraiser.

The program schedule will be posted on the web site. For a full list of confirmed speakers, registration, hotel and transportation information, visit the ThyCa web site at www.thyca.org.

Graves' Disease Conference October 24-26

Graves' disease is another thyroid disease, and the National Graves' Disease Foundation will hold its annual patient/family conference on October 24-26, 2003, at the same hotel where the Thyroid Cancer Survivors' Conference is taking place. For information about the Graves' Disease Conference, see

ThyCa Member C.J. Hartman Holds a Personal "Rally for Research"

This past spring, ThyCa held its first "National Rally for Research," uniting the efforts of those raising funds to support ThyCa's thyroid cancer research funds. Although not everyone who wanted to was able to participate on May 18, the designated rally day, ThyCa supporters have found creative ways to hold their own individual "Rally for Research" days.

One such supporter is C.J. Hartman, a ThyCa member from Colorado. C.J. is one of five individuals on the staff of her school who have been diagnosed with thyroid cancer. After her June recurrence of thyroid cancer, C.J. was determined to pursue her plan to race in the local Rattlesnake Triathlon. The triathlon includes a one-mile swim, twenty-three-mile bike ride and five-mile run—considered an Olympic distance.

Worried about telling co-workers about her recurrence, C.J. decided to use the triathlon as her personal Rally for Research. "I began by explaining that I would be doing my next triathlon the following weekend and I wanted to dedicate this particular one to ThyCa because it would be my longest and most difficult one, not only in distance but because of the mental challenge I was facing with the recurrence. I also explained that even though there were five of us on staff affected by thyroid cancer, it is still considered rare and that money for research is very limited compared to breast cancer and other cancers. I asked that if they wished to offer their support in some way, to skip the personal gifts to me at this time. I would be most appreciative if they would elect to donate to ThyCa in all of our honors and I would in turn dedicate my next race."

On July 13, C.J. finished the triathlon in 3 hours and 11 minutes. Drawing inspiration from professional triathlete and thyroid cancer survivor Karen Smyers, C.J. wisely notes "It is not winning the race, it is finishing the race" that counts.

You can help ThyCa raise funds for research by holding a "Rally for Research" in your community. The rally can be organized around a sports event ("Strike Out" thyroid cancer with a softball game, "Putt Out" thyroid cancer with a round of golf), bake sale ("Sweeten the Pot" for thyroid cancer research) or car wash ("Shine Our Way to Research"). For other great ideas, visit the Rally for Research page on the ThyCa web site.

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> is an all-volunteer nonprofit 501(c)(3) service organization providing support, education, and communication for thyroid cancer survivors, family members and friends.

We welcome new volunteers and members at any time.

ThyCa News Nuggets

Welcome ThyCa's Newest Local Support Group

On September 13, 2003, ThyCa's most recently formed local support group meets for the first time in Silicon Valley, California! The group will meet in Redwood City on the second Saturday afternoon of each month. **Gail Schuler**, the facilitator, will welcome you. Some of you have met Gail already, at our conferences and in her role as a volunteer for our toll-free number. For information on the meeting time and location, visit the "Support Group" page on ThyCa's web site, www.thyca.org.

Thyroid Cancer Awareness Week:

September 15-21, 2003

Help spread information about the importance of thyroid cancer detection, treatment and follow-up. **Thyroid Cancer Awareness Week is sponsored by ThyCa.** Printable fliers for distribution were created by our volunteers and are available on the ThyCa web site. Leave them at your doctor's office, community center, supermarket, and other public announcement location, and help inform others about thyroid cancer. Let others know during Awareness Week and any time during the year!

South Florida's "Thyroid Disease and You"

Free Forum on September 18

On September 18, 2003, the American Thyroid Association, together with the Thyroid Foundation of America, ThyCa, and other thyroid organizations are sponsoring an educational forum on thyroid disease. Medical professionals will be on-hand to answer questions. In addition to the panel of physician experts, the program will include **Leah Guljord**, ThyCa Low Iodine Cookbook Editor and our Support Groups Coordinator. **Joan Axthelm**, ThyCa South Florida Support Group Facilitator, is also taking part. The forum takes place 7 p.m. to 9 p.m. at The Breakers Hotel, One South County Road, Palm Beach, Florida. For a flyer with more information and driving directions, visit the Calendar section of the ThyCa web site, www.thyca.org.

Membership Messenger

ThyCa members are receiving the latest Membership Messenger newsletter. A round of thanks to ThyCa volunteers **Cheri Wallace Lindle**, facilitator of our Anaplastic Thyroid Cancer Listserv, and the Messenger Team of **Karen Ferguson**, **Leah Guljord**, **Mary Rose Weckerle**, and **Lee Sinnett**, for all their help with Messenger.

New Additions to ThyCa's Web Site

Frequent visitors to ThyCa's web site have noticed the addition of new health care information and several journal abstracts, articles, reports, and other material. While you're looking, check out some of our Home Page sections.

- We've added more information from the National Cancer Institute about risk factors, diagnosis, treatment, and side effects. You'll find it in the sections titled **Newly Diagnosed** and **Thyroid Cancer Types**, listed on the left side of our Home Page.
- As another example, a new addition to our **Links** section, under **Tests and Levels**, is the consensus report titled "*Use of Thyroglobulin Testing for Monitoring Low Risk Patients with Papillary Thyroid Cancer.*" The thyroid cancer specialists who developed this report, published in April 2003, include ThyCa Medical Advisors **Paul Ladenson, M.D.**, and **Carole Spencer, Ph.D.**, as well as five of our other thyroid specialist conference speakers.
- In our **Links** section, we added a link to *Thyroid Today* <www.thyroidtoday.com>, which has continuing education for clinicians through patient case studies and other materials.
- Also in the **Links** section are several articles/abstracts about Thyrogen, including a recent addition.
- Our **News** section continues to add articles as well. In addition, each issue of *ThyCa JOURNEYS* is downloadable in its print version from the **Newsletters** section.
- Our **Calendar** lists coming events, and our **Local Support Groups** section gives meeting dates and places as well as information about upcoming guest speakers.

ThyCa's E-Mail Support Groups

Are Bigger and Better!

Did you know that ThyCa's largest e-mail support group now has more than 1,300 participants? The support group is a general forum for patients to discuss thyroid cancer issues and find support. For information about our seven e-mail support groups, each for a different situation with thyroid cancer, visit our web site.

Connections Growing

A growing number of organizations are connecting their readers with ThyCa's free support services and resources.

- *Coping with Cancer Magazine* has published conference and workshop announcements and last year had a feature article about ThyCa.
- *CURE Magazine*, a free general cancer magazine at www.curetoday.com, also links patients and families to ThyCa.
- *Thyroid Today* at www.thyroidtoday.com, an educational web site mainly for continuing education for physician clinicians, links readers to ThyCa and our conference; our Medical Advisor **R. Michael Tuttle, M.D.**, is an editor.

You're Invited to the Auction Action at ThyCa's Thyroid Cancer Research Fundraising Dinner and Auction!

We look forward to welcoming you all to our 2nd Annual **Fundraising for Research** Dinner and Auction on Friday, October 24th, as our 6th International Conference begins in Houston Texas. We promise you an evening of fun, food, and friendship, while you help us to continue our Research Fundraising efforts for all thyroid cancer. This informal event was a terrific success last year, raising funds for thyroid cancer research and bringing us closer to a world without thyroid cancer.

The cost for the entire evening is \$60, of which \$40 is tax deductible. Please visit the ThyCa web site for more information and to send in your registration. You won't want to miss out on this terrific event!

Our Silent Auction will feature items from \$10 gift cards up to varied items for your home and family, as well as wonderful gifts for all occasions.... or one could say... everything from soup to nuts...literally! There will be something for everyone, our promise to you. We encourage you to bring bids from friends and family, and anyone else not able to attend who might wish to participate in absentia.

We have received some wonderful Auction items, adding two new categories this year, of interest to everyone.

The first is the addition of Support Group Baskets, represented by 10 of our Support Groups nationwide. Support Groups were invited to participate, pick a theme, and jointly fill their baskets with suitable items. This very exciting new entry is chaired by Marion Hammond of Baltimore, Maryland, who's done a superb job of detailing and carrying out this project. Our thanks and appreciation go to Marion for her desire to be involved with Fundraising for Research, and adding to our knowledge that one person ...can make a difference!

The second new category is Jewelry...of both the serious, and not-so-serious varieties. We think that you will all have a grand time choosing from our wonderful selections here.

From our dedicated and very talented ThyCa members, come several exquisite and unique offerings. These include a hand-crocheted afghan, a handmade quilt featuring the ThyCa colors, several handcrafted Jewelry sets, and a hand knit woman's sweater.

Our Auction offerings also include 3 cruises with Holland America... one 10-night outside space for 2 people to your choice of the Caribbean, Mexico, Panama Canal, or Canada/New England. And two 7-night cruises for 2 people, outside space, to your choice of Alaska, the Caribbean, Mexico, or Canada/New England. Plus vacation packages to Seattle, Vancouver, BC, Canada, and Aruba in the Caribbean.

We'll have details on the web site.

If you would like to donate an item for the Auction, please contact our Fundraising Chair Joni Eskenazi by e-mail at jeskenazi@thyca.org. We would love to hear from you. Joni also will be happy to send you invitation letters and remittance envelopes to give to others.

Thanks always for your support and we look forward to welcoming you in person at the Benefit.

IF YOU CAN'T ATTEND....

There are several ways you can help...sponsor a dinner ticket for a friend, send a bid with a friend, or send a donation for Thyroid Cancer Research. Thank you for your help!

Have You Checked Out the ThyCa Web Site Lately?

Our web site (www.thyca.org) has hundreds of pages, plus links to lots more, and is growing every month. It's chock full of information for newcomers, long-term survivors, caregivers, and family members.

The low-iodine cookbook is available free for downloading and provides recipes for even the most hypothyroid chef.

Our webmistress **Betty Solbjor** updates our web site nearly every week. Log on now to see what you've been missing and check back regularly for important updates about our conference and more.

