# HIGHLIGHTS AND DETAILS

# The 10th International Annual Thyroid Cancer Survivors' Conference

October 19-21, 2007 — San Francisco, California Sponsored by ThyCa: Thyroid Cancer Survivors' Association, Inc<sub>SM</sub>

# **OVERVIEW**

- We are pleased to report that nearly 500 people attended the conference from 37 states, 5 provinces of Canada, and Brazil. This is a new record high attendance!
- Participants included survivors of every type of thyroid cancer—papillary, follicular, medullary, and anaplastic, and variants—as well as family members. Attendees included people in all age groups. They ranged from people being tested for possible thyroid cancer to survivors of many decades. Many had never met another person with thyroid cancer before.
- The conference theme was "Support, Education, Communication, and Hope through Research."
- Our goal was to give everyone the latest knowledge and understanding about this disease, its treatment and management, and research advances. Our hope was that wherever people were from, or whatever their circumstances with their thyroid cancer, they would gain in knowledge and would find a sense of community during the weekend, among new friends.
- More than 60 presenters from 17 states and Canada led more than 100 sessions, generously contributing their time and expertise.
- For the first time at a ThyCa conference, continuing education credits were available for nurses.
- More than 90 volunteers helped onsite at the conference, and many additional volunteers who were unable to attend helped throughout the year with outreach, publicity, and publications.
- In the program booklet and at the volunteer appreciation reception, ThyCa honored the memory of those who lost their lives to thyroid cancer during the past year.
- More than 200 people attended the Saturday evening Dinner/Auction Fundraiser, which successfully raised funds for thyroid cancer research. The wife of a medullary thyroid cancer survivor gave an inspiring message about the crucial importance of research and how it offers hope for cures for all thyroid cancer.
- Many people have sent thank you e-mails since the conference. One example:
  - "This was my first conference and I must say, I learned so much, networked with a lot of wonderful people from all across our great country, and had just a splendid time. It is exciting to be a part of the ThyCa family/community and I look forward to sharing with our support group the next time we meet."
- Most attendees who completed evaluation forms gave the conference an overall rating of 5 (excellent) on a 5-point scale. The average rating was 4.9. Some people wrote in ratings of 6 or 7; these were counted as 5 for averaging.
- We were gratified to receive such positive comments and to receive so many helpful suggestions for future conferences. Please remember, we invite you to send your suggestions/comments to <a href="mailto:conference@thyca.org">conference@thyca.org</a> throughout the year!
- Below you'll find more highlights, followed by details about the program, speakers, exhibitors, and donors, plus comments and suggestions from the evaluation forms.
- Many thanks to everyone who helped make the conference such a big success.

-Gary Bloom and Cherry Wunderlich, Conference Co-Coordinators

# **MORE DETAILS**

- The nearly 500 participants came from Alabama, Alaska, Arizona, California, Colorado, Connecticut, Delaware, District of Columbia, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Kansas, Kentucky, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, Tennessee, Texas, Virginia, Washington, Canada's provinces of Alberta, British Columbia, Manitoba, Ontario, and Saskatchewan, and Brazil.
- The 65 speakers and workshop leaders included four past presidents of the American Thyroid Association and several members of ThyCa's Medical Advisory Council. Our presenters all generously donated their time to ThyCa Conference 2007. Occasionally, we have last-minute schedule changes that result. We do our best to accommodate all speaker changes. Sometimes, this can result in program "flow" changes. Our speakers included:
  - 25 physicians including specialists in endocrinology, surgery, medical oncology, nuclear medicine, and pathology, including experts in every type of thyroid cancer
  - 2 dentists
  - an endocrine laboratory director and thyroglobulin researcher
  - a pharmacist
  - 2 mental health professionals
  - a nurse
  - specialists in Reiki, music, and other approaches to wellbeing
  - the president of the Canadian Thyroid Cancer Support Group (Thry'vors)
  - survivors of every type of thyroid cancer
  - family members and caregivers affected by every type of thyroid cancer
- The conference had more than 100 sessions. These included over 50 sessions on thyroid cancer care and research, plus sessions on coping skills and complementary approaches, survivor/caregiver roundtable discussions on coping with thyroid cancer, and 10 sessions on getting involved in support services, raising awareness, and research fundraising and advocacy.
- Most participants who returned evaluation forms gave the conference the highest possible overall rating —5. The overall conference ratings averaged 4.9. The most frequent rating given for individual sessions was 5; most scores were 4 or 5.
- People heard about ThyCa and the conference from numerous sources. These included ThyCa's web site, other web sites; e-mailings; doctors and flyers in doctors' offices and hospitals; flyers in community locations; and ThyCa volunteers, members, friends, local support groups, the news media, and mailings.
- Scholarships to cover the registration fee were available on request, to make the conference available to everyone regardless of ability to pay. Grant funding plus the nominal registration fee cover printing, postage, audiovisual equipment, and the other basic conference expenses.
- Year round Financial Sponsors included ThyCa's Members, Constituents, and Individual Donors, Genzyme Therapeutics, Amgen, AstraZeneca, Abbott Laboratories, Exelixis, Inc., Fleming and Company, King Pharmaceuticals, KRONUS, and OXiGENE. Our thanks to all our donors for their valued support.
- For the first time at a ThyCa conference, continuing education credits were available for nurses, for designated sessions where speakers provided learning objectives. At some sessions, as many as 15 nurses were in attendance. Attendees were able to receive continuing education credit for about 12 hours.
- We will use suggestions received on the evaluation forms, verbally at the conference, and in e-mails since then for added topics and other improvements as the planning continues for next year's conference, October 17-19, 2008 in St. Louis, Missouri.

- More than 100 volunteers planned and ran the conference. At the conference, they handled the set-up the day before the conference and the packing up after the conference; registrations, exhibits, and spirit items, session hosting, and dinner/auction. They wrote the Daily Update Bulletins, hosted and introduced the presenters; and helped attendees with their questions and needs. All this followed more than a year of brainstorming, inviting speakers, preparation of materials, arranging supplies, posting information on the web site, publicizing the conference by e-mail, phone, and mail and numerous other details. The ThyCa Conference 2007 Planning Committee members were Gary Bloom, Ron Grafman, Leah Guljord, Jan Halzel, Wendy Hull, Tammy Kilhullen, Cheri Lindle, Peggy Melton, Gail Schuler, and Cherry Wunderlich,
- Our heartfelt thanks to everyone who helped make ThyCa Conference 2007 so successful. We couldn't have done it without so many people's wonderful involvement and help! We look forward to seeing you in St. Louis next year.

# **CONFERENCE DETAILS**

- A. THE PROGRAM AND SPEAKERS
- **B. EXHIBITORS**
- C. DONORS
- D. MORE COMMENTS FROM THE EVALUATION FORMS

# A. THE PROGRAM AND SPEAKERS

#### **PROGRAM**

- The complete program schedule is on this page of the web site: <a href="http://www.thyca.org/program07.pdf">http://www.thyca.org/program07.pdf</a>
- The more than 100 sessions included over 50 sessions on thyroid cancer care and research, more than a dozen sessions on coping skills and complementary approaches, more than 30 survivor/caregiver roundtable discussions including both open discussions and specific themes related to coping with thyroid cancer, and 10 sessions on getting involved in support services, raising awareness, and research fundraising and advocacy.

### **SPEAKERS**

Joel Amromin, ThyCa Volunteer, CA

Shirley Baker, ThyCa Volunteer, MD

Rita Banach, President, Canadian Thyroid Cancer Support Group (Thry'vors), ON, Canada

Lee Bard, ThyCa Volunteer, TN

Gary Bloom, ThyCa Executive Director, MD

Michael Bouvet, M.D., Surgeon, University of California, San Diego, CA

Sara Brenner, ThyCa Volunteer, VA

**Gregory Brent, M.D.,** Endocrinologist, UCLA School of Medicine & VA Greater LA Healthcare System, Los Angeles, CA

Mark S. Chambers, M.S., D.M.D, Dentist and Oral Oncologist, University of Texas, M.D. Anderson Cancer Center, TX

Orlo H. Clark, M.D., Surgeon, University of California, San Francisco, CA

Peter Crane, ThyCa Volunteer, WA

Amy D'Ambrosio, Psy.D., Psychologist, Tucson, AZ

Michael Dubrow, ThyCa Volunteer, NJ

Tom Engle, ThyCa Volunteer, MO

Michelle Feng, ThyCa Volunteer, CA

**Scott M. Fishman, M.D.,** Anesthesiologist, Chief, Division of Pain Medicine, University of California, Davis, CA

Robert F. Gagel, M.D., University of Texas, M.D. Anderson Cancer Center, Houston, TX

Alan Gilstrap, Genzyme Therapeutics, Cambridge, MA

Jessica E. Gosnell, M.D., Endocrine Surgeon, University of California, San Francisco, CA

Ron Grafman, ThyCa Volunteer, MD

Francis S. Greenspan M.D., Endocrinologist, University of California, San Francisco, CA

Jon Guljord, ThyCa Volunteer, FL

Leah Guljord, ThyCa Volunteer, FL

Janis I. Halzel, Pharm.D., Pharmacist, Consensus Medical Communications, CO

Jerome Hershman, M.D., Endocrinologist, VA Greater Los Angeles Healthcare System, CA

David Ho, ThyCa Volunteer, CA

Jessica Jones, ThyCa Volunteer, MA

Electron Kebebew, M.D., F.A.C.S, Surgeon, University of California, San Francisco, CA

Tammy Kilhullen, ThyCa Volunteer, TX

Roselle Kovitz, ThyCa Volunteer, WA

Paul R. Krakovitz, M.D., Otolaryngologist, Cleveland Clinic Foundation, Cleveland, OH

Michael A. Levine, M.D., F.A.A.P., F.A.C.P., Pediatric Endocrinologist, Cleveland Clinic Foundation, OH

Patti Malloy, ThyCa Volunteer, OH

Erika Maslan, M.F.T., Family Therapist, The Wellness Community, Walnut Creek, CA

Ernest L. Mazzaferri, M.D., M.A.C.P., Endocrinologist, University of Florida, Gainesville, FL

I. Ross McDougall, M.D., Ph.D., Nuclear Medicine Physician, Stanford University Medical Center, CA

Bryan McIver, M.B. (M.D.), Ph.D., F.R.C.P., Endocrinologist, Mayo Clinic, Rochester, MN

Lee Melton, ThyCa Volunteer, TX

Peggy Melton, ThyCa Volunteer, TX

Mira Milas, M.D., Endocrine Surgeon, Cleveland Clinic Foundation, Cleveland, OH

David Myssiorek, M.D., F.A.C.S., Otolaryngologist, New York University Cancer Center, NY, NY

Lisa A. Orloff, M.D., Otolaryngologist, University of California, San Francisco, CA

Mary Catherine Petermann, ThyCa Volunteer, GA

Kim Samuel, ThyCa Volunteer, PA

Louise Samuel, ThyCa Volunteer, NJ

Gail Schuler, ThyCa Volunteer, CA

Manisha H. Shah, M.D., Medical Oncologist, Ohio State University College of Medicine, Columbus, OH

Peter A. Singer, M.D., Endocrinologist, USC Ambulatory Care Health Center, Los Angeles, CA

Betty Solbjor, Reiki Master/Practitioner, Bach Foundation Registered Practitioner, & Interfaith Minister, MA

Carole A. Spencer, Ph.D., F.A.C.B., Laboratory Director, University of Southern California,

Los Angeles, CA

Clayton Twigg, ThyCa Volunteer, OH

Rose Twigg, ThyCa Volunteer, OH

Dwight Vicks, ThyCa Volunteer, NY

Jo Walker, ThyCa Volunteer, AZ

Samuel A. Wells, M.D., Surgeon, Washington University School of Medicine, St. Louis, MO

Sheila Williams, ThyCa Volunteer, TN

Kenneth A. Woeber, M.D., Endocrinologist, University of California, San Francisco, CA

**Pat Wolfe, R.N., M.B.A.,** Director of Patient Care Services, Pathways Home Health and Hospice, Sunnyvale, CA

Cherry Wunderlich, ThyCa Volunteer, MD

John R. Wunderlich, M.D., Bethesda, MD

Michael Yeh, M.D., Endocrine Surgeon, UCLA School of Medicine, Los Angeles, CA

# B. EXHIBITORS AND RESOURCE TABLE MATERIALS

### • ThyCa: Thyroid Cancer Survivors' Association

- ThyCa's Materials in English and Spanish
- Pediatric Backpack Display: Backpack from Tim C. of Maine, pediatric thyroid cancer survivor

# • Guest Exhibitors and Resource Material Contributors

American Association for Cancer Research

American Association of Clinical Endocrinologists

American Cancer Society
American Thyroid Association

AstraZeneca

Canadian Thyroid Cancer Support Group (Thry'vors)

Coping with Cancer Magazine

Exelixis, Inc.

Genzyme Therapeutics

The Hormone Foundation and The Endocrine Society

Hypoparathyroidsim Association

Lance Armstrong Foundation

National Organization for Rare Disorders

Thyroid Foundation of America

Thyroid Head and Neck Cancer Foundation (THANC)

#### C. DONORS

# IN APPRECIATION FOR YOUR GENEROUS SUPPORT of ThyCa Conference 2007

#### FINANCIAL SPONSORS

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#### THANK YOU TO

- All our Volunteers
- The Individual Donors of Beautiful Items for our Conference and the Auction

# OUR SPECIAL THANKS ALSO TO the entire staff of the Sofitel San Francisco Bay Hotel

# D. MORE COMMENTS FROM THE EVALUATION FORMS

#### OVERALL COMMENTS

- -- Enjoyed the wealth of knowledge. Great delivery!
- -- Great information
- --Everything is very well run. Interaction with patients, caregivers, and MDs was very helpful.
- -- Keep up good job!
- --Your efforts toward organizing really paid off. Thank you!
- --Excellent.
- --I liked the roundtable-open mike.
- --Each session had key points of value to me.
- --Speakers wonderful and patient.
- -- Thank you to all the doctors and volunteers.
- -- Thanks for getting such outstanding speakers. I love ThyCa!
- -- Very informative and helpful.
- --Physician-patient communications discussion; received frank and very intelligent help for many difficult problems in this area.
- --You have put on a great conference!
- --I learned about issues that had troubled me for years. The doctor was not depressing and made his presentation in a cheerful manner.
- --Doctor has the candid ability of delivery; lots of information with a tremendous sense of humor.
- --I'm thankful that we have such great speakers!
- --Good information, easy to understand
- --All sessions helpful
- --I really enjoyed the sessions and learned a lot of good info.
- --Fantastic get-together lots of great info.
- --Thank you to all ThyCa workers/volunteers!!!! Thank you! Thank you ThyCa! Thank you ThyCa volunteers and leaders and board!!!
- --I can see that as I become more knowledgeable the conference will still be helpful.
- -- About one session... Wow. Wow! What a power package!
- -- Thank you so very much.
- --Everyone was so kind and organized.
- -- Thank you for an excellent conference!
- --Wealth of information.

### TOPIC AND PROGRAM COMMENTS AND SUGGESTIONS

(Editors' Note: In addition to the comments, we've included responses in italics.)

- -- Lengths of sessions great! The conference will continue these session lengths and times.
- --It was nice when the speaker restated the questions in case we couldn't hear the question. We will add this suggestion to the guidelines for session hosts.
- --Cross-reference and index the sessions. We will try to do this in next year's program schedule. Please keep in mind that there may be last-minute speaker session changes.
- --Ask all presenters if their materials can be posted on <a href="www.thyca.org">www.thyca.org</a>. We ask, and usually speakers prefer that the web site add general content from many sessions rather than individual session materials.
- --Would be helpful for speakers to have a handout of their presentation. --Have talks available on a CD (could sell them). Some speakers bring handouts, and we're happy to copy them for attendees. Our web site adds content from the conference and other sources throughout the year. To ensure attendee privacy, we don't video or audio record sessions.
- --Speakers all very good but topics overlap. --For multi-part sessions, have the agenda posted and slides available. --Less duplication of materials in schedule. --Tell people the difference between roundtables and doctor's talks. --Maybe on the program next year indicate the intended participants of each session or list what will be emphasized. We will try to clarify session titles as well as differences in types of sessions. Some overlap is intentional, as attendees choose different sessions during each timeslot.
- --Check with presenters what aids they need (like flowcharts). We do. Sometimes there are last minute requests. We will add aids if needed.
- --Have some "beginners" sessions for newly diagnosed with medical experts. We'll try to increase these.
- --Have a complete lunch break. We encourage attendees to take breaks as needed during the day. The days are full, including optional Lunch and Learn Sessions, due to requests for more topics and sessions than otherwise possible in the 6 rooms, and in the course of what is already a very long day.
- --Possibility to have a doctor/professor attend roundtable. We'll encourage our doctors to attend sessions.

  Some attendees prefer sessions without physicians for certain topics. When doctors attend roundtables, the sessions usually evolve into Ask a Doctor sessions.
- --Often 2 sessions I wanted to go to were at same time. --Perhaps basic info could be covered at roundtable or first session so presenters didn't repeat that. This is a frequent comment, We try to schedule more than one session on the most requested topics, to give everyone more chances to hear speakers on the topics of their choice. Also, not everyone attends all the same sessions, so information that one person hears repeated is new to someone else. We prefer to hear that there are 2 or more sessions at the same time that people want to attend, rather than there are no sessions of interest. We always encourage people to travel with someone else so you can split up and attend 2 sessions at the same time. Additionally, you can post questions about a session you didn't attend in Conference Central. This is a great way to meet someone!
- --I also appreciate the opportunity to listen to and have access to the pediatric physicians since my son is affected. The access to specialists for varied types and situations with thyroid cancer is a valuable aspect of the conference.

# **Added Topic Suggestions:**

(Editors' Note: Thank you. The topic suggestions are very helpful. We use them when inviting speakers.

Individual sessions, especially Ask a Doctor sessions, also give opportunities to ask about varied topics.)

- --More on test results, reading and understanding results.
- -- More about TgAb and how it will affect long-term Tg testing.
- --More about parathyroid issues, hypoparathyroid symptoms, and longterm side effects. Also calcium, Vitamin D, osteoporosis. What should we be watching out for?
- --More sessions about hypothyroidism.
- -- Nasolacrimal obstruction and dry eyes.
- -- Can we please have nuclear medicine doctors attend the conference to learn more about low-dose RAI?
- -- Do a second presentation on pain management.
- --Latest research for those of us who have recurrence, the cells no longer throwing off thyroglobulin and no longer absorbing radiation.
- --I see a medullary track. How about 1 or 2 sessions for follicular and its variants. A class on patients who have a combination of papillary and follicular thyroid cancer.

- -- More Reiki sessions.
- --Food and diet on a continuous basis.
- --Session on the psychological impact for young adults.
- --How can we learn more about managing/screening for other cancers without radiation / or minimal radiation "related" to thyroid cancer. (breast/ salivary/bladder/colon, etc.)
- -- Another session specifically for men. A session on women's issues.

# Suggestions for additions to our host/moderator guidelines:

(Editors' Note: We will add these. Thank you.)

--Moderator control so session starts on time. --Shorten speaker introductions, as the booklet has the details. --It was helpful when facilitators kept questions moving along (some questions could get long and personal). --Ask presenters to complete their talk and slides before taking questions. --Have speakers use microphone.

Again, thank you. These are big helps for our planning.

# FACILITY, FOOD, CONFERENCE CENTRAL, AND OTHER COMMENTS/SUGGESTIONS

### **Hotel Suggestions:**

--1. Some rooms were too small. 2. One room was too warm. 3. Food plan at lunch by hotel could have been better—several lines, more staff. 4. Hotel nearer to shopping centers, malls, and restaurants. We will add these to our checklists for planning, as well as discussions with staff at future hotels. Each hotel is different. Some hotel details need to be arranged on site at the conference. Others can be arranged in advance. We arrange as much as possible in advance.

# Food and Beverage Suggestions:

- --1. More water at 4 p.m. 2. Have more items without dairy at lunch and the reception. 3. Thank you for having vegetarian sandwiches. 4. Free lunch was OK; the chosen sandwich was not. 5. I'd pay more for the conference for free coffee. 6. Room coffee makers missed. We will explore these with future hotels. We'll try for more varied choices with regards to the food. Regarding coffee, it's much less expensive for those who like coffee to purchase it individually, as hotels add a high service charge for coffee in pots. Additionally, some attendees like coffee and others do not. In the future we will see if it's possible to arrange inexpensive coffee by the cup, as part of the a la carte choices, for those who like coffee.
- --1. MTC breakfast meeting not included on evaluation. Breakfast should have been set up before meeting, not during, with noise. 2. Dinner for meddies enjoyable; shop for restaurant and prices. Breakfast had been arranged, but didn't happen due to an oversight. The last minute breakfast was a speedy reaction. We continually strive to improve our special events.
- -- Sat. night dinner had high ticket price. This is the only fundraiser associated with the conference, and the ticket price is due to the hotel's banquet fee.

## **Conference Central Room and Other Suggestions**

- --A message board would be nice, also a way to find others from one's home area. We usually have a message board. Thanks for the reminder!
- --Thank you for the scholarship. Very helpful. You're welcome. That's why scholarships, to cover the registration fee, are available on request. The registration form has a blank for requesting a scholarship. We want everyone who wants or needs to attend to be able to attend. All we ask is, if you can help with conference related costs, that you do so.
- --Give flexibility for walk-in attendees so that they can go directly to sessions and complete registration later, when they have a break between sessions. We agree and plan modifications for the future to do this.
- --Perhaps a "conference buddy" and "mentor" arrangement would be helpful for first-time attendees. We agree. Greeting and welcoming newcomers and walk-ins are important parts of the conference experience. We want attendees to have the feeling of being in a support group when they arrive, during registration, and throughout the conference.
- -- Thank you, Tammy from TX, for your help! You're welcome. Tammy's involvement is greatly appreciated!

--If you haven't already, send flyers to endo MDs to give to their patients. We have more than a thousand doctors and group practices on our mailing list. Please send us doctors' mailing addresses and we'll be glad to mail flyers and other ThyCa materials.

During and after the conference, we received further helpful suggestions for welcoming speakers and greeting walk-in attendees and everyone who comes to our "Conference Central" room so that they'll more quickly reach their sessions.

### MORE COMMENTS SINCE THE CONFERENCE:

Thank you to the participants who have sent e-mails since the conference. Two of the e-mails:

# • From a physician speaker:

"I get far more out of the ThyCa meetings than I give."

### • From a first-time attendee:

"A BIG "Thank You" to the entire Board and Conference Planning Committee for a wonderful conference. This was my first conference but it will not be my last.

The presenters were competent, personable, and approachable. The workshops were spot on, covering all of the relevant topics that survivors are looking for.

The dinner/auction was so much fun and it was very invigorating to see how much the attendees care about ThyCa by their generous donations.

I will be sending in my annual membership and offer my assistance to ThyCa to serve in any needed capacity.

Have a wonderful rest of the year and be well."

#### THANKS AGAIN TO EVERYONE!

HOPE TO SEE YOU IN ST. LOUIS, MISSOURI, OCTOBER 17-19, 2008 AT THE 11<sup>TH</sup> INTERNATIONAL THYROID CANCER SURVIVORS' CONFERENCE.

**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, dedicated to education, communication, support, awareness for early detection, and thyroid cancer research fundraising and research grants.

Throughout the year, ThyCa provides free local support groups, e-mail support groups, a person-to-person network, an award-winning educational web site, a toll-free survivors' telephone number, a free low-iodine cookbook downloadable from the web site, and many other free publications in English and Spanish for thyroid cancer survivors and families.

ThyCa sponsors year-round awareness activities and, each September, Thyroid Cancer Awareness Month. ThyCa also organizes research fundraising and sponsors thyroid cancer research grants, open to researchers and institutions worldwide. ThyCa welcomes new volunteers and members at any time.

For more information, visit our web site of ThyCa: Thyroid Cancer Survivors' Association, Inc., at http://www.thyca.org, call toll free at 1-877-588-7904, write to ThyCa: Thyroid Cancer Survivors' Association, Inc., P.O. Box 1545, NY, NY 10159-1545, or e-mail to thyca@thyca.org.

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