

HIGHLIGHTS AND DETAILS
The 11th Annual
International Thyroid Cancer Survivors' Conference
October 17-19, 2008 — St. Louis, Missouri
Sponsored by ThyCa: Thyroid Cancer Survivors' Association, Inc.SM

OVERVIEW

- We are honored to report that the 11th International Thyroid Cancer Survivors' Conference was highly successful, bringing together several hundred people from 34 states, Canada, and Netherlands. Once again, the conference had outstanding attendance and speakers.
- The conference theme was "Support, Education, Communication, and Hope through Research."
- Participants included survivors of every type of thyroid cancer—papillary, follicular, medullary, 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 previously met another person with thyroid cancer.
- Our goal was to give everyone in-depth opportunities to learn from distinguished experts and understand the latest knowledge 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.
- 67 presenters from 18 states and Canada led more than 100 sessions, generously contributing their time and expertise.
- Once again, continuing education credits were available for nurses.
- In the program booklet and at our volunteer appreciation reception, ThyCa honored the memory of those who lost their lives to thyroid cancer during the past year, as well as one of our caregiver volunteers. This year we honored and remembered 59 wonderful people.
- More than 70 volunteers helped onsite at the conference. Dozens of additional volunteers who were unable to attend helped throughout the year with outreach, publicity, and publications.
- Our Saturday evening Dinner/Auction Fundraiser successfully raised more than \$35,000 for thyroid cancer research. Cheri Lindle, who lost her stepfather to anaplastic thyroid cancer; Sheryl Pascal, thyroid cancer survivor and Mrs. New Jersey American Beauty 2008, and Rose Twigg, wife of anaplastic thyroid cancer survivor Clayton Twigg, all gave inspiring messages about how thyroid cancer research is urgently needed, and offers hope for cures for all thyroid cancer.
- Many people have sent thank you e-mails since the conference. Our thanks to all of you.
- 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. Most session ratings were 4s and 5s. The average overall rating for all sessions was 4.4.
- 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 conference@thyca.org 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-Coordinator

MORE DETAILS

- Conference participants came from Alabama, Arizona, California, Colorado, Connecticut, District of Columbia, Florida, Georgia, Illinois, Indiana, Iowa, Kansas, Kentucky, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New York, North Carolina, Ohio, Oklahoma, Oregon, Pennsylvania, South Carolina, Tennessee, Texas, Virginia, Washington, Wisconsin, Canada's provinces of Newfoundland and Ontario, and Netherlands.
- **67 distinguished speakers and workshop leaders came from 18 states and Canada and included several members of ThyCa's Medical Advisory Council.** Our presenters all generously donated their time to ThyCa Conference 2008. Occasionally, we have last-minute schedule changes. We do our best to accommodate all speaker changes. Sometimes, this can result in program "flow" changes. Our speakers included:
 - 24 physicians including specialists in endocrinology, surgery, medical oncology, nuclear medicine, and pathology, including experts in every type of thyroid cancer
 - 2 dentists
 - a nurse
 - 4 mental health professionals
 - specialists in Reiki, QiGong, art therapy, humor, and other approaches to well-being
 - a pharmacist
 - financial specialists
 - 3 attorneys
 - survivors of every type of thyroid cancer
 - family members and caregivers affected by every type of thyroid cancer
- **The conference offered more than 100 session choices, with 6 sessions in different rooms at most time periods during the day.** These included more than 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 several sessions on getting involved in ThyCa's 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 on a scale of 1 to 5. The most frequent rating given for individual sessions was 5; most scores were 4 or 5. The overall session ratings averaged 4.4.
- People told us that they 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, AstraZeneca, Genzyme Therapeutics, Abbott Laboratories, Bayer/Onyx Pharmaceutical, Exelixis, Inc., Jones/ King Pharmaceuticals, KRONUS, OXiGENE, Sigma-Aldrich, Toshiba Ultrasound, and Unithroid Direct. **Our thanks to all our generous donors for your valued support, which sustains and strengthens our services.**
- Continuing education credits were again available for nurses, for designated sessions where speakers provided learning objectives.
- 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 16-18, 2009 in Boston, Massachusetts.

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- 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. More than a year of planning involving 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 2008 Planning Committee members were Gary Bloom, Tom Engle, Leah Guljord, Jan Hazel, Tammy Kilhullen, Roselle Kovitz, Peggy Melton, Mary Norbut, Mary Catherine Petermann, Sandy Triplett, Theresa Wickerham, and Cherry Wunderlich,
- Our heartfelt thanks to everyone who helped make ThyCa Conference 2008 so successful. Everyone's wonderful involvement and help made a big difference! We look forward to seeing you in Boston 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 web site page: <http://www.thyca.org/ProgramPreview2008.pdf>
- 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 sessions on getting involved in support services, raising awareness, and research fundraising and advocacy.

SPEAKERS

Janet Adams, ThyCa Volunteer, TX

Joel Amromin, ThyCa Volunteer, CA

Rita Banach, BSc., DSC., DTATI, Art Therapist, Canadian Thyroid Cancer Support Group (Thy'vors), Inc., Toronto, ON, Canada

Oralia V. Bazaldua, Pharm.D., FCCP, BCPS, Pharmacist, University of Texas Health Science Center at San Antonio, San Antonio, TX

Gary Bloom, ThyCa Executive Director, MD

James H. Boyd, M.D., ENT Surgeon, St. John's Mercy Medical Center, St. Louis, MO

Marcia S. Brose, M.D., Ph.D., Medical Oncologist, University of Pennsylvania, Philadelphia, PA

Rebecca Brown, M.D., Endocrinologist, University of Chicago Medical Center, Chicago, IL

Christine Ciletti, ThyCa Volunteer, FL

John Cucarese, ThyCa Volunteer, OH

Rosa M. Davila, M.D., Pathologist, St. Louis, MO

Mary Debenedetti, R.N., ThyCa Volunteer, MO

Teresa L. Deshields, Ph.D., Psychologist, Psycho-Oncology Service, Barnes-Jewish Hospital, St. Louis, MO

Eddie Dodson, Genzyme, Cambridge, MA

Michael Dubrow, ThyCa Volunteer, NJ

Tom Engle, ThyCa Volunteer, MO

Paul Etamab, ThyCa Volunteer, CA

James R. Etzkorn, M.D., Endocrinologist, St. John's Mercy Medical Center, St. Louis, MO

Kevin Ferris, M.S.W., L.C.S.W., C.M.C., Wellness Community, St. Louis, MO

Perry W. Grigsby, M.D., Nuclear Medicine Physician, Washington University School of Medicine, St. Louis, MO

Elizabeth Grubbs, M.D., Surgeon, University of Texas, M.D. Anderson Cancer Center, Houston, TX

Jon Guljord, ThyCa Volunteer, FL

Leah Guljord, ThyCa Volunteer, FL

Ian D. Hay, M.D., Ph.D., Endocrinologist, Mayo Clinic, Rochester, MN

Margaret A. Hesse, J.D., Esq., Attorney, Tueth, Keeney, Cooper, Mohan & Jackstadt, P.C., St. Louis, MO

Mimi I. Hu, M.D., Endocrinologist, University of Texas, M.D. Anderson Cancer Center, Houston, TX

Lauri Huber, ThyCa Volunteer, IL

Uzma Z. Khan, M.D., Endocrinologist, University of Missouri, Columbia, MO

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

Cheri Lindle, ThyCa Volunteer, OK

Patti Malloy, ThyCa Volunteer, OH

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

Lee Melton, ThyCa Volunteer, TX

Peggy Melton, ThyCa Volunteer, TX

Pam Mendenhall, ThyCa Volunteer, IA

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

Jeffrey F. Moley, M.D., Surgeon, Washington University School of Medicine, St. Louis, MO

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

Shannon Nanna, Psy.D., Psycho-Oncology Psychologist, Siteman Cancer Center, Barnes Jewish Hospital, St. Louis, MO

Robert G. Oesch, Esq., Attorney, Riezman Berger, P.C., Clayton, MO

Sherryl Pascal, Mrs. New Jersey American Beauty 2008-2009, NJ

Ron Rain, D.Min., Certified Qi Gong Instructor, Wellness Community, St. Louis, MO

Elizabeth J. Reinsch, Ph.D., A.C.S.W./ L.C.S.W., University of Missouri Extension, St. Louis, MO

Matthew D. Ringel, M.D., Endocrinologist, Ohio State University College of Medicine, Columbus, OH

Joseph Scharpf, M.D., Surgeon, Cleveland Clinic Foundation, Cleveland, OH

Mary Seemueller, ThyCa Volunteer, VA

M. Julie Shanahan, Esq., Attorney, Social Security & Disability Issues, Crowe & Shanahan, St. Louis, MO

Steven I. Sherman, M.D., Endocrinologist, University of Texas, M.D. Anderson Cancer Center, Houston, TX

Edward B. Silberstein, M.D., Nuclear Medicine Physician, Internist, Medical Oncologist, Hematologist, University of Cincinnati, Cincinnati, OH

Jennifer A. Sipos, M.D., Endocrinologist, University of Florida Shands Cancer Center, Gainesville, FL

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

Julie Ann Sosa, M.D., M.A., Surgeon, Yale University School of Medicine, New Haven, CT

Beatriz Tendler, M.D., Endocrinologist, University of Connecticut Health Center, Farmington, CT

Sandy Triplett, ThyCa Volunteer, MO

R. Michael Tuttle, M.D., Endocrinologist, Memorial Sloan-Kettering Cancer Center, New York, NY

Clayton Twigg, ThyCa Volunteer, OH

Rose Twigg, ThyCa Volunteer, OH

Irini E. Veronikis, M.D., Endocrinologist, St. Louis, MO

Dwight Vicks, ThyCa Volunteer, NY

Kathryn Brubaker Wall, ThyCa Volunteer, NC

Steven G. Waguespack, M.D., Endocrinologist, University of Texas, M.D. Anderson Cancer Center, Houston, TX

Vanda White, ThyCa Volunteer, MD

Theresa Wickerham, ThyCa Volunteer, MO

Sheila Williams, ThyCa Volunteer, TN

Andrew Wolken, D.D.S., Dentist, St. Louis, MO

Christopher M. Wolken, D.D.S., Dentist, St. Louis, MO

Cherry Wunderlich, ThyCa Volunteer, MD

B. EXHIBITORS AND RESOURCE TABLE MATERIALS

• ThyCa: Thyroid Cancer Survivors' Association

- ThyCa's Materials in English and Spanish and Pediatric Backpack Display

• Guest Exhibitors and Resource Material Contributors

American Cancer Society • American Thyroid Association •
AstraZeneca • Canadian Thyroid Cancer Support Group (Thy'vors) •
Exelixis, Inc. • Genzyme Therapeutics •
Hypoparathyroidism Association • University of Missouri Extension •
TOSHIBA Ultrasound • The Wellness Community •

C. DONORS

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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 Sheraton Westport Hotel – Lakeside Chalet

D. MORE COMMENTS FROM THE EVALUATION FORMS

D. COMMENTS FROM THE EVALUATION FORMS, CLOSING SESSION, AND E-MAILS RECEIVED AFTER THE CONFERENCE

OVERALL COMMENTS

- An outstanding group, unbelievable. I was blown away. It was beyond informative. I want to do more.
- Very good experience.
- This was my first conference and so glad I was able to attend.
- Informative.
- Helpful to learn spectrums of all sides, all treatment options, differences of opinion; valuable to learn when there's no one way.

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- Found out about new things happening that aren't yet being widely done; treatment for the future.
- We are messengers who can go tell doctors.
- We can show the conference booklet to our doctors, to show the program and speakers.
- Nice to have sessions that were not about cancer; helpful for stress relief: Reiki, QiGong, Labyrinth, Myers-Briggs, for example.
- I went away feeling very informed and well connected.
- My wife and I found the conference very useful. Probably we will come again in Boston. Thanks for organizing.
- We were astounded at the quality of people and information at this Conference (our first one).
- This year's conference was as wonderful as all the others I have attended. I really want to thank everyone who works so hard to make it a success. Your efforts are most appreciated.
- I enjoyed the conference. All of the physicians that presented were excellent.
- After 5 years of dealing with medullary thyroid cancer, we were thrilled to finally meet other meddies face to face. The information presented by the physicians and other speakers was priceless. Just to get details about the drug trials from those involved has really given us hope. No doubt that there is still much to do, but it seems that we are on the right track. We are very thankful to EVERYONE who had a hand in planning this conference and to all of the speakers. We are already planning to attend next year in Boston. Blessings to all.
- I was so happy to meet everyone and hope that I can attend next year in Boston.
- My daughter and I attended our first ThyCa conference. It was VERY informative and we met some new friends. I'm really glad we went. It makes me feel better about our upcoming thyroid appointment.
- As always it was a great weekend and I was especially pleased to meet so many that had only been an "online name" to me before the conference. I hope those unable to attend will consider going to Boston for the 2009 conference.
- Another super conference this year -- so well organized with such a great line-up of MTC specialists from around the country
- Congratulations to everyone who worked so hard on this year's conference. You could see how much time, effort, and expertise went into the weekend. Know that this weekend's conference made everyone proud to be connected to this organization. My hat is off to the committee.
- Wonderful.
- FANTASTIC. I only wish I would have been mindful enough to volunteer but I hope to be able to help out a bit for next year's conference.
- The conference was wonderful! We learned so much. Thank you so much for all the work that went into it.
- What an exceptional, once-a-year opportunity it is to have this many MTC experts come speak to our Meddie audience. Thanks so much to all the enthusiastic ThyCa people for their months of planning and hard work leading up to the conference.
- Conference was EXCELLENT! It's an exciting time in thyroid cancer research. 10 years ago there were NO THYROID CANCER CLINICAL TRIALS! Now there are several, including ATC.
- There was something for everyone. Each session had a variety of choices; in some cases it was hard to choose. I felt that the very first round table discussion/getting to know people was the most valuable.
- Amazing that I've learned more in one day here than in 2 years of doctor appointments! Thank you! I can see already why people return year after year. VERY informative.
- The sessions I attended were helpful. This was my first conference.
- This is my first Conference. It is good.
- Excellent.
- All presenters were well prepared and very informative!
- Thank you.
- Excellent. Thank you so much to all the committee members, presenters, and support staff. Affordable. Met great people. See you in Boston 2009.

- Very good information! New to this (diagnosed in August).
- Extremely informative.
- It was good that the doctors didn't give too much medical speak or technical information. Good balance of information.
- Great conference. Great speakers, with lots of diversity.
- ALL GOOD. It is better to have more Questions and Answers than a long presentation.
- More of the same! I learned so much! This is my first conference. It was fantastic.
- Thank you so very much. This was incredibly empowering.
- Keep up this conference. It is extremely beneficial.

COMMENTS ABOUT PARTICULAR SPEAKERS AND SESSIONS

- Best speaker I have ever heard at a conference. Very Knowledgeable. Most significantly, empathetic and very patient.”
- Amazing, priceless!
- Super. Down to earth and personal.
- Awesome. Super presentation.
- Excellent.
- Very informative.
- Fabulous! I love having docs who can think through the whole process and are not intimidated by questions.
- Doctor spoke slow, easy to understand, and explained how she has changed her words to patients based on her experiences learning with a relative.
- Doctor was very helpful and answered all questions.
- Quite talented.
- Wonderful presenter. A great addition to ThyCa. Very knowledgeable! Friendly! Informative!
- Very helpful session because it provided up-to-date information on the new treatment options. Easy to understand. A good teacher, while providing excellent, up-to-date information.
- Excellent.
- Very nice and thorough.
- Interesting to hear some other points of view.
- Good information. Good R & D roundtable – lots of good info.
- Doctor was wonderful in answering questions.
- Very comforting and inspiring with a wealth of useful information. I only wish I would have had the courage to ask the doctor to join us for dinner.
- Best at answering questions of a practical nature.
- Really helpful and well organized.
- A little confusion regarding PET scans and type of surgery. It seems that different doctors prefer different approaches.
- Very informative! Keep people like this doctor coming to ThyCa conferences!
- I learned more in one hour of listening to the doctor than 2.5 years of visiting various doctors. Great, so informative and very personable.
- Super.
- Informative, easy-to-understand, and the most applicable to where I am now in my treatment.
- Magnifique! Interesting that we could listen to 5 or 6 top MTC experts, basically on same subject, and learn new ideas from each! Keep inviting top docs!
- Excellent as usual.
- Great explanations of follow-up.
- Excellent, new perspective.
- So incredibly awesome! Thank them and keep them coming!
- Very clear and informative.
- Remarkable. Passion, energy, and compassion for patients was very impressive. Extremely patient while responding to questions. I'm grateful I had the opportunity to meet her.

- Doctor infused humor along with great information.
- One speaker didn't have enough specific information. Didn't have some basic information.
- Opening roundtable most helpful Friday. I thought that learning what others are going through can help me in my situation and vice versa. It helps to know that I can find out about other care people are getting from doctors.
- Open Mike Roundtable most helpful. Great information!
- Complementary approaches were great. Gave me a great feeling and info to put that into my life.
- Art therapy was relaxing presentation that brought out all the underlying emotions. Wonderful!
- Art therapy was very helpful for several survivors – some healing took place.
- Art therapy very good. Unfortunately due to lack of time only 3 people could present their work. I'd prefer less time for art and more time to receive her helpful observations.
- Humor and Healing was something different and fun. QiGong was also a little bit different.
- I didn't get the full benefit of the humor and healing workshop because I was late, but it was wonderful for the part that I was able to attend.
- Humor and healing session was fun.
- I enjoyed all the alternative therapies greatly. Survivors will benefit greatly from these if used. Labyrinth presentation was fantastic. Myers-Briggs presentation also very enlightening.
- Informal conversation session didn't work out; few attended.
- Patient/Physician Relationships session helped me to realize that getting second opinions is okay to do as well as asking more questions from my doctors.
- Open discussions really help to hear other experiences.

TOPIC AND PROGRAM COMMENTS AND SUGGESTIONS

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

- For Saturday late afternoon sessions, don't have conference team members leading sessions as they may be needed to help elsewhere such as auction setup.
Ideally, we'll have a separate team of volunteers for auction setup. We'll be mindful of this excellent input
- Have another session on how to form a support group. *This session is very important. It is difficult to find a good time to offer it in the program. Next year we will offer some informal times to have support group development discussions, even if they become one-to-one times.*
- Continue to have dentists, not only physicians.
We will continue to try to include one or more dentists in each year's program.
- (session moderator comment)...lunchtime session difficult because people kept arriving throughout session ... felt should update them... discussion did not really follow the topic and it ended up to be more of a general type of discussion. *We're always reviewing the program with an eye toward timing and coordination. We are considering a slightly longer break at lunch time to allow people interested in attending a lunch-and-learn session more time to get their food.*
- Sessions seem too diffused. Plenary sessions would have been better, with motivational/inspirational speakers. All other conferences I've been to have plenary sessions rather than nothing but individual ones. Panel format of several speakers would be good. *Thanks for your suggestion. Most people at the conferences have requested a breadth of opportunities for each time slot. We are considering having plenary sessions at certain times of the day. Additionally, attendees have preferred not having panel format discussions.*
- Longer breaks. *Thanks for this suggestion.*
- Staying on topic. 1. One talk was not on the listed topic. 2. Didn't stay on topic in session.
We're sorry about this. We review topics with speakers in advance to try and make sure they agree with their topic, and the time slot.
- We think that sessions focused on well-defined topics in lecture format are most helpful. Question and answer sessions tend to have disparate inchoate information not easily digestible as to relevance, importance, and context within such a vast specialty.
Both speakers and most attendees have requested that sessions be interactive.

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- Some sessions did not stay on the scheduled topic and Q and A segments were more like public consults than consideration of generalizable topics.
We will review the moderator guidelines. The moderator needs to try and keep the session on track, as well as ensuring that no attendee dominate a session, nor turn it into a personal consultation.
- Too many repeat sessions on new drugs and MTC trials. Once or twice is enough.
Thank you. This was based on requests from last year's attendees, and MTC group leadership. We will review and adjust accordingly.
- I like a speaker who can use simple language to explain a complicated medical issue. In one session, some materials were too academic. *We apologize for this. While some attendees like technical materials, we request that the speakers try to target us as a patient group rather than as medical professionals.*
- Make sure the "laughing and humor" session is in a room away from other rooms. The noise is distracting when listening to the speaker. It sounds like a great class, but when trying to concentrate on a more serious speaker, it's a little hard (made me wish I was in the laugh class!)
Thanks for this helpful room assignment tip.
- It would be good to have people recommend their doctors, ultrasound facility, surgeons in the area where they live. *When we develop the program, we invite local area specialists to introduce them to area attendees. In our speaker list we also try to create a balance among experts from local, regional, and distant centers.*
- Handouts. 1. We would like each presenter to offer a short selected bibliography for the topic. 2. Want handouts, including of Powerpoint presentations. 3. Handout from the speaker; we can take notes, too. 4. Wish the presenters had handouts at every session.
We request handouts from each speaker and will continue to do so. As you noticed, some don't use handouts or Powerpoint presentations while some do. Some who use a Powerpoint presentation prefer not to share their slides with the group as they feel that the slides need the verbal explanations. When the speakers shared handouts, we offered them at the session. Each year the handout participation is different.
- Breaks. 1. Have a four-hour break one afternoon for emotional rebound, time to process it. 2. Arrange a local outing the day before or after the conference. 3. More time to sightsee. How about a 4-day conference so we can visit and sightsee too! 4. Offer a shuttle service to area attractions for a fee on Friday and Saturday night.
Most attendees want to stay at the meeting and to have session choices throughout the day. For this reason we don't have a large break in the schedule. Instead, people are welcome to skip sessions whenever they choose and schedule their own breaks or afternoons off. We're looking into some sightseeing options for next year in Boston. Historically, very few people have shown interest in sightseeing. We're certainly willing to look into this again.
- It would be helpful if the doctors had a break between sessions so we could finish our questions. *This is true. However, many of them need to leave the conference when they finish their sessions. Additionally, many of the doctors provided sessions for very different groups of attendees (different types of thyroid cancer and different circumstances with thyroid cancer), making it important to have them available for all groups of survivors.*
 - After each session a roundtable to hear others' experiences and share own experiences would be valuable. *We try to have roundtables after doctor led sessions when the timing and room availability allow. However, most people given this choice choose to go to the next doctor-led session instead of the roundtable.*

Added Topic Suggestions:

(Editors' Note: Thank you. The topic suggestions are very helpful. We use them when inviting speakers. The Ask a Doctor sessions and the question periods in other sessions also give opportunities to ask about varied topics.)

- Speech pathologist on voice issues. *Great suggestion! We're working on this now.*
- More on familial differentiated thyroid cancer.
We hope to have additional sessions on this topic in Boston.

- More information on mRNA.
This was a new topic in St. Louis. We hope there will be more discussion on this in Boston.
- Session by a radiation oncologist. *Great suggestion. We're working on this now.*
- Graves' Disease and autoimmune diseases. Causes, what to expect through the years, does it ever go into remission or completely go away when thyroid is removed. I've had conflicting answers to this. *These questions should be directed to the speakers who focus on Management over the Long Term.*
- Pain issues: advance neuron modulation stimulators.
- Cowden's syndrome.
- Roundtable on coping with multiple health issues at the same time. Have it on Friday or Saturday. *That was the original plan, but a roundtable speaker had to cancel her Friday session.*

Suggestions for audiovisuals and room set up.

- Microphones. 1. Use lavalier mikes. 2. Have speakers use microphones. 3. Sound problems at beginning of a session.
Speakers had microphones in nearly all rooms. The only rooms without a microphone were the very small breakout sessions. We will encourage the room moderator to get the speakers to use the microphones. We weren't aware of sound problems. Please report these issues in conference central as quickly as possible so we can try to remedy them.
- Slide projectors sometimes not functioning. It should be working before each session starts. Some presenters used some of the same slides.
We test the projection equipment every morning when it is setup. We'll try and be more vigilant next year. We apologize for any and all technical problems.
- Hosts should (1) know how to use the remote control and (2) explain it to the speaker before beginning. Let's also make little instruction sheets. *Great suggestion.*
- Make sure that speakers have water at their spot where they are speaking. *Great suggestion.*
- Nice to have tables in the rooms to write on and to have the hotel provide notepads.
Most people prefer that there not be tables because they take up space, and potentially reduce the number of people who can attend some sessions. Some hotels will provide pens and paper, while others won't. Thanks for pointing this out. We'll work on this for Boston.

Suggestions for additions to our host/moderator and facilitator guidelines:

(Editors' Note: We will add these points to the guidelines. Thank you.)

- 1. End sessions on time. Missed the morning announcements and updates because the early bird sessions ran over. 2. We ran out of time. 3. Ended up running long in several presentations and had to rush through or didn't finish theirs. 4. Session facilitators need to be trained. Some of them read intros in a monotone, and mispronounced the speaker's name. Some didn't keep track of time or questioners. 5. Keep track of time. 6. Wish some can limit time to ask questions, because others should have time to ask questions. Be polite. Someone shouldn't just talk about their own problem.
We try to end sessions on time. As you see above, sometimes that means sessions end before the speaker finishes covering the topic. We'll work with session moderators to introduce the speakers more enthusiastically and accurately.
- Roundtables. 1. Make sure each roundtable has a facilitator. 2. Sessions all good except a lunchtime session where initially no leader arrived and then someone came after half the time had elapsed and had nothing prepared.
Thanks for this input. We had one topic where we had to replace a last-minute cancellation.
- Person in and out and on cell phone was distracting.
We're sorry. We will request that attendees be more mindful of their neighbors.
- Have no photo-taking with flash during sessions. *Thanks for this suggestion.*
- Have evaluation forms in the back of each room to reduce the traffic in Conference Central.
Again, thank you. There were forms on hallway tables, and having them in session rooms as well will also be helpful. These evaluation forms are big helps for our planning.

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

Hotel Comments and Suggestions:

1. Shuttle very easy from airport. 2. Great coming in on shuttle. 3. Hotel well picked. 4. Audio excellent at hotel. 5. Location good; could drive there from Denver. 6. Shuttle to shopping was a long trip. 7. Quick access from airport avoided cab fare. 8. One afternoon a noisy party and music next door to a session room made it difficult to hear the speakers. 9. Hotel management should not schedule loud music/party next to a speaker/conference room. 10. Please warm up the conference rooms! 11. Loud singing and music next to session room one afternoon; poor planning by hotel. 12. All the rooms need to be together and no other groups should be in rooms near the ThyCa rooms. 13. Next year try to have all the meeting rooms on the same level. Other groups shouldn't be near us.

Excellent comments! The shuttle worked very well this year. We're very sorry for the loud noise in comment #8, 9 and 11. We have reported this back to the hotel. Unfortunately, unless we reserve all the meeting space at a hotel, we can't stop the hotel from offering space to another group. That said, this was the only year this has been such a problem. Regarding room locations, it is very difficult to find a hotel with all the meeting space with different room sizes on the same level, and all in the same area.

Food, Beverage, and Lunchtime Suggestions:

Lunch. 1. Better lunch arrangement in order to get to lunch session. 2. Consider lunch option payable in advance. 3. Retrieving of lunch (boxed) was a bit disorganized. Didn't get to really listen well to session while eating and couldn't take notes on it. Would rather have a lunch half hour time with no sessions. 4. One luncheon meeting was very distracting with continuous plastic containers and pop cans opening. 5. Faster serving of lunch. 6. It would be nice to have a continental breakfast and snack breaks. Also, coffee and drinks would've been nice, too. I'd be more than happy to pay more to get more.

Excellent suggestions. We'll work on refining our lunch options. Each hotel works with us differently with regard to food. Some have been willing to offer convenient breakfast and lunch options. With regard to coffee and drinks, and snack breaks, they are typically very expensive in hotels. Most attendees don't want to pay extra for this.

Conference Central Room and Other Suggestions

1. Best Conference Central I've experienced. *Thank you!*
2. Add label to attendee folder: "This folder belongs to" (attendee can add his or her name).
Great suggestion.
3. Add information to nametags of ThyCa volunteers listing what they do for ThyCa so that people know whom to ask about specific topics (Support Group Facilitator, Toll-Free Number Volunteer, E-Mail Team Coordinator, etc.). *Great suggestion.*
4. Make better use of caregivers in Conference Central, so that survivors can attend sessions.
We will do our best to better benefit from the help from all the wonderful people who offer to help with onsite coordination. Thank you to everyone!
5. Print out forms and materials for Conference Central and Resource Tables well before the conference.
Thanks for this suggestion. We continue to try to finalize many materials in advance.
6. Have a memory board where people can put up tributes to people or their favorite quote to share with everyone.
We had a board in conference central for this purpose. We'll do a better job of publicizing this next year.
7. A. Extra paper in folders would be great for note-taking. B. Capped pens would be better than click pens. *Good idea to include writing paper in the registration folder. Thanks for this suggestion.*

Fundraiser Comments and Suggestions

- Drawings. 1. Baskets and daily drawings went well. Do it again. 2. Set deadline for auction items of October 1 and say that items received after that will be in the daily drawing. 3. Give people a ticket for the drawing if they turn in their evaluation.
Thanks for this feedback.

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- Dinner/Auction. 1. Well organized and inspiring. 2. Needed to be left up longer to allow people to continue to bid. Need checkout earlier for people leaving earlier. Avoid having people wait till bid numbers arrive. 3. Wonderful evening. Had a great time.

Thanks for this feedback.

Outreach Suggestion

Advertise the nurses' continuing education credits in advance. Consider an added charge for them.

This year this opportunity came together in the last week, making it difficult to get this word out.

We're working on this already for Boston with the hope that we will be able to publicize this opportunity much earlier.

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

THANKS AGAIN TO EVERYONE!

**HOPE TO SEE YOU IN
BOSTON, MASSACHUSETTS,
OCTOBER 16-18, 2009**

AT THE

12th INTERNATIONAL THYROID CANCER SURVIVORS' CONFERENCE.

Sheraton Ferncroft Hotel, 50 Ferncroft Road, Danvers, Massachusetts

Watch www.thyca.org for details and updates.

ABOUT ThyCa: Thyroid Cancer Survivors' Association, Inc. (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, 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, free patient information packets, 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, which are open to researchers and institutions worldwide. ThyCa has awarded research grants each year since 2003.

Funding for our free support services, outreach, awareness campaigns, and research grants comes from membership dues, individual donations, and contributions from businesses and other organizations. More than 300 people volunteer their time to ThyCa. ThyCa welcomes new volunteers and members at any time.

For more information and free materials, visit our web site of ThyCa: Thyroid Cancer Survivors' Association, Inc., at 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.