HIGHLIGHTS AND DETAILS — THYCA 2000
Third Annual Thyroid Cancer Survivors’ Conference
September 8-10, 2000 — Chevy Chase, Maryland

Sponsored by ThyCa: Thyroid Cancer Survivors’ Association, Inc., an all-volunteer non-profit 501 (c)(3)
organization dedicated to support, communication, and education for thyroid cancer survivors, their families,
and friends

www.thyca.org
thyca@thyca.org

OVERVIEW

We are delighted to report that 216 thyroid cancer survivors and family members came to the conference from
22 states, the District of Columbia, and the United Kingdom. That’s quite a range!

ThyCa 2000 featured more than 60 sessions led by 46 presenters from 11 states, the District of Columbia, and
Canada.

Our hope was that wherever people were from, they would find a sense of community during the weekend,
among new friends. During the conference, we heard people say

“Wow! What an unbelievable experience this is!”
“Exceptional presenters.”
“This has been amazing.”
“I love the synergy of this conference.”
“Worth traveling a long way for.”
“I am not alone.”

Most evaluation forms gave the conference an overall rating of 10 on a 10-point scale. We were gratified to
receive such positive comments and to receive so many helpful suggestions for next year’s conference.

One thyroid cancer survivor wrote:

“Thank you for organizing this wonderful conference. Meeting other people going through the same
things I am has been tremendously psychologically helpful. The doctors that spoke were first rate. All
were helpful in answering questions and taking the time to explain concepts and issues clearly. It also
gave me the ability to see an overview of how the disease operates, changes, and develops, which I know
will better equip me to talk to my doctors about my treatment. Thanks again!”

Below you’ll find more highlights, followed by comments and suggestions from the evaluation forms, plus
details about the program, speakers, exhibitors, and donors.

Many thanks to everyone who helped make the conference such a huge success. We did a great job!
—ThyCa 2000 Planning Committee

HIGHLIGHTS

• The 216 thyroid cancer survivors and family members came from Arizona, California, District of Columbia,
Florida, Hawaii, Georgia, Illinois, Indiana, Kentucky, Louisiana, Maryland, Massachusetts, Michigan, New
Hampshire, New Jersey, New York, North Carolina, Ohio, Pennsylvania, Rhode Island, Texas, Virginia, West
Virginia, and the United Kingdom.

• The 46 speakers and workshop leaders included
  --16 physicians prominent in thyroid cancer care and research;
  --2 pharmacists;
  --3 social workers;
  --a hospital chaplain;
  --3 attorneys specializing in health insurance and employment issues;
specialists in nutrition, fitness, Reiki, yoga, T’ai Chi, massage, art therapy, and other approaches to well-being;  
several thyroid cancer survivors; and  
family members and caregivers.

Our presenters all generously donated their time to ThyCa 2000. They came from the District of Columbia, Georgia, Kentucky, Maryland, Massachusetts, Missouri, New Hampshire, New Jersey, North Carolina, Pennsylvania, Texas, Virginia, and Ontario, Canada.

- Sixty-two people returned evaluation forms. Almost three-quarters gave the conference the highest possible overall rating—10. The overall conference ratings were all 8, 9, or 10. Every session received 30% or more ratings of 10. Many received half or more ratings of 10. People heard about ThyCa SM and the conference from the Internet, family members, friends, support groups, physicians, newspapers, and a mailing. We are using the suggestions for added topics and other improvements as we plan for next year’s conference, September 21-23, 2001.


- More than 35 individuals also supported the conference through financial contributions and donations of supplies.

- More than 50 volunteers planned and ran the conference. They handled the registrations, raffle, and ThyCa SM spirit items; collated the Daily Update Bulletins, hosted and introduced the presenters; and helped attendees with their questions and needs. All this followed many months of brainstorming, inviting speakers, producing materials, putting details on the website, selecting the Spirit items, organizing the raffle, photocopying handouts, stuffing goodie bags with donated items, and communicating through constant emails and sometimes some phone calls.

- Our heartfelt thanks to everyone who helped with ThyCa 2000. We couldn’t have done it without you!

CONFERENCE DETAILS
A. THE PROGRAM AND PRESENTERS  
B. EXHIBITORS  
C. DONORS  
D. MORE COMMENTS FROM THE EVALUATION FORMS

A. THE PROGRAM AND PRESENTERS

Friday, September 8
8:00 a.m.  Registration Desk Opens
8:45 a.m.  Welcome and Conference Opening  
Megan Stendebach, Conference Coordinator
9:00 — 10:45 a.m.
121  Survivors, Families, and Friends: Opening Session  
Gary Dionne, ThyCa SM Volunteer

11:00 a.m.—12 noon
Survivors’ Roundtable: Papillary and Follicular
Jeffrey Moley, M.D., Surgeon, Washington University School of Medicine
Survivors’ Roundtable: Medullary
Survivors’ Roundtable: Anaplastic
12:15 —1:00 p.m.
Lunch
1:15— 2:30 p.m.
Research Update: Experimental Approaches to Aggressive and Dedifferentiated Thyroid Cancers
Kenneth B. Ain, M.D., Endocrinologist, University of Kentucky Medical Center
Diagnosing Thyroid Cancer: Fine Needle Aspiration, Evaluating Tissue After Surgery
Yolanda Oertel, M.D., Pathologist, Washington Hospital Center; Barry M. Shmookler, M.D., Pres. & CEO, Academic Oncology Resources
Survivors’ Families: Taking Care of Ourselves, Too
Jon Mathis, ThyCa SM Volunteer
2:45—4:00 p.m.
Self-Care and Coping with Thyroid Cancer Over the Long Term: Roundtable
Joy Paul, ThyCa SM Volunteer
Ask a Pharmacist
Nayahamka McGriff, Phar.D., National Institutes of Health
Ask a Doctor
Kenneth D. Burman, M.D., Endocrinologist, Washington Hospital Center
4:15—5:30 p.m.
Thyrogen Roundtable
Kenneth D. Burman, M.D., Endocrinologist, Washington Hospital Center; Todd Foster, Thyrogen Marketing Manager, Genzyme Corporation
Medullary Issues
Douglas Ball, M.D., Endocrinologist, The Johns Hopkins Medical Institutions
Massage Therapy: Caring Through Touch
Carol and Greg Skolnik, Massage Therapists
If You’re New to Thyroid Cancer: Things You Should Know About Your Health Care
Nicholas J. Sarlis, M.B. Ph.D., M.D., Endocrinologist, National Institutes of Health

Saturday, September 9
8:00 a.m. Registration Desk Opens
212  **Reiki— Individual Sessions**  
Betty Solbjor, ThyCa SM Webmistress, ThyCa SM Board Member

213  **Other Complementary Approaches to Well-Being**

215  **Tai Chi**  
Sue Gurland, L.Ac., Acupuncturist, ThyCa SM Volunteer

**8:45 a.m. Daily Overview**  
Megan Stendebach, Conference Coordinator

**9:00—10:15 a.m.**

221  **Future Trends in Thyroid Cancer Care:**  
**Current Techniques, Messenger RNA and Other New Developments in Monitoring**  
Matthew D. Ringel, M.D., Endocrinologist, Washington Hospital Center

222  **Complementary Approaches to Well-Being**  
Sue Gurland, L.Ac., Acupuncturist, ThyCa SM Volunteer; Nancy Harazduk, M.S., LICSW, Center for Mind-Body Medicine; Cheryl Hurwitz, L.CSW-C, Body Psychotherapist, Musician, Performance and Recording Artist

223  **Survivors’ Families: Taking Care of Ourselves, Too**  
Diane Blake, ThyCa SM Volunteer

224  **Survivorship Issues: Communicating with Our Doctors and Support Structure**  
Judith Bernardi, M.S.W., Ph.D., American Cancer Society

225  **Reiki— Individual Sessions**  
Betty Solbjor, ThyCa SM Webmistress, ThyCa SM Board Member

**10:30—11:45 a.m.**

231  **If You’re New to Thyroid Cancer:** **Things You Should Know about Your Health Care**  
Paul W. Ladenson, M.D., Endocrinologist, The Johns Hopkins Medical Institutions

232  **Ask a Pharmacist**  
Frank Puchino, Ph.D., National Institutes of Health

233  **Insurance Roundtable: Health Care for All**  
Richard D. Carter, Esq., Attorney, Carter & Coleman; Michael Knipmeyer, Esq., Attorney, Jacob Burns Community Legal Clinic, George Washington University

234  **Thyroid Cancer: A Long-Term Survivor’s Perspective**  
M. Sara Rosenthal, thyroid cancer survivor and author of *The Thyroid Sourcebook* and *The Thyroid Sourcebook for Women*

235  **Reiki— Individual Sessions**  
Betty Solbjor, ThyCa SM Webmistress, ThyCa SM Board Member

**12:00 noon—1:15 p.m.**

Lunch

**Health Care Forum**
U.S. Representative Connie Morella of Maryland
Gary Bloom, ThyCa SM Board Chair

1:30—2:45 p.m.
241 Ask a Surgeon about Papillary and Follicular
David Myssiorek, M.D., Surgeon,
Long Island Jewish Medical Center

242 Ask about Medullary
Vera Ray, Facilitator of Internet Medullary
Thyroid Cancer Support Group

243 Thyrogen Roundtable
Monica Skarulis, M.D., Endocrinologist,
National Institutes of Health;
Todd Foster, Thyrogen Marketing Manager, Genzyme Corporation

244 ThyCa SM Support Groups: Starting One,
Facilitating One
Ric Blake, ThyCa SM Support Groups Coordinator,
ThyCa SM Board Member

3:00—4:15 p.m.
251 Papillary Roundtable
Monica Skarulis, M.D., Endocrinologist,
National Institutes of Health

252 Follicular Roundtable
Nicholas J. Sarlis, M.B., Ph.D., M.D., Endocrinologist,
National Institutes of Health

253 Medullary Roundtable
Vera Ray, Facilitator of Internet Medullary
Thyroid Cancer Support Group

254 Anaplastic Roundtable
Kenneth B. Ain, M.D., Endocrinologist,
University of Kentucky Medical Center

255 Art Therapy for Care Providers
Krirstinah Talus-Ayala, B.F.A., M.S.Ed., LCPC,
Director, Center for Creativity

4:30—5:45 p.m.
262 Living with Hypothyroidism
Mary Shomon, author of Living Well with
Hypothyroidism: What Your Doctor Doesn’t Tell You...
That You Need to Know

263 Physical Conditioning and Nutrition
Ali Gelani, Fit-One

264 Art Therapy for Survivors
Krirstinah Talus-Ayala, B.F.A., M.S.Ed., LCPC,
Director, Center for Creativity

Sunday, September 10
8:00 a.m.  Registration Desk Opens
311  Yoga
Teresa Campama,
ThyCa SM Delaware Valley Support Group Facilitator

312  Reiki — Individual Sessions
Betty Solbjor, ThyCa SM Webmistress

313  Other Complementary Approaches to Well-Being
314  Specialty Group Discussions
315  Tai Chi
Sue Gurland, L.Ac., Acupuncturist, ThyCa SM Volunteer

8:45 a.m.  Daily Overview and ThyCa Songs
Megan Stendebach, Conference Coordinator

9:00—10:15 a.m.
321  Ask a Nuclear Medicine Doctor about Radioiodine Treatment, the Post-RAI Period, Salivary Problems, PET Scans
Douglas Van Nostrand, M.D., Nuclear Medicine Physician, Washington Hospital Center

322  External Beam Radiation: When, How, Other Things to Know
Robert White, M.D., Washington Hospital Center

323  Survivors’ Families and Friends: Taking Care of Ourselves, Too
Dominica Roth, MSW, LCSW-C, Social Worker, National Institutes of Health

324  Reiki — Individual Sessions
Betty Solbjor, ThyCa SM Webmistress

325  Thyroid Basics: What Does Your Thyroid Gland Do for You?
Arturo R. Rolla, M.D., Endocrinologist, Beth Israel Deaconess Medical Center

10:30—11:45 a.m.
331  Ask a Nuclear Medicine Doctor about Radioiodine Treatment, the Post-RAI Period, Salivary Problems, PET Scans
Douglas Van Nostrand, M.D., Nuclear Medicine Physician, Washington Hospital Center

332  Medullary Roundtable
Robert F. Gagel, M.D., Endocrinologist, University of Texas M.D. Anderson Cancer Center

333  Workplace Issues and Employment Rights
Patricia Smith, Esq., Attorney

334  ThyCa SM: Getting Involved, Reaching Out, Spreading the Word
Gary Bloom, ThyCa SM Board Chair
335  Reiki — Individual Sessions
    Betty Solbjor, ThyCaSM Webmistress, ThyCaSM Board Member

11:45  Lunch and Conference Feedback.
    Megan Stendebach, Conference Coordinator

12:45—1:45 p.m.

341  Research Update: The Low-Iodine Diet
    Nancy Sebring, M.Ed., R.D., Clinical Research Dietitian,
    National Institutes of Health

342  Humor and Healing
    Andrea Cumberland, TC, Staff Chaplain,
    Holy Cross Hospital

343  ThyCa Website Roundtable
    Betty Solbjor, ThyCaSM Webmistress, ThyCaSM Board Member

344  AOL Thyroid Cancer Mutual Support Group
    Roundtable
    Karen Ferguson, ThyCaSM Board Member;
    Donald Margouleff, M.D., Nuclear Medicine Physician,
    North Shore University Hospital

2:00-2:45 p.m.

355  Roundtable and Closing Workshop
    Gary Dionne, ThyCaSM Volunteer

B. EXHIBITORS

American Cancer Society
    11331 Amherst Avenue, Silver Spring, MD 20902
    301-933-9350  www.cancer.org

Genzyme Therapeutics
    One Kendall Square, Cambridge, MA 02139-1562
    617-252-7500  www.genzyme.com

Human Biological Data Interchange (HBDI)
    1880 JFK Boulevard, 6th Floor, Philadelphia, PA 19103
    800-345-4234  www.hbdi.org

Knoll Pharmaceutical Company
    3000 Continental Drive—North, Mount Olive, NJ 07828-1234
    800-240-3820  www.knoll-pharma.com

Metro Region PET Center at Woodburn Nuclear Medicine
    3289 Woodburn Road, Annandale, VA 22003
    703-207-7520

National Institutes of Health
    9000 Rockville Pike, Bethesda, MD 20892
    Cancer Information Service: 1-800-4-CANCER (1-800-422-6237)  www.nih.gov
C. DONORS

IN APPRECIATION
FOR YOUR GENEROUS SUPPORT
OF THYCA 2000

FINANCIAL SPONSORS
American Cancer Society
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Just J Studios, Leesburg, Virginia

COMPUTER CORNER SPONSOR
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THANK YOU TO
The Donors of Prizes for our Raffle Rainbow Fundraiser

OUR SPECIAL THANKS ALSO TO
Andi Janowski
and the entire staff of the National 4-H Conference Center

D. MORE COMMENTS FROM THE EVALUATION FORMS
OVERALL COMMENTS

- Outstanding!
- Great job. Thanks to everyone on the committee.
- Conference was great and I was relieved to meet people who could relate to what I had gone through.
- Excellent conference and look forward to next year.
- I don’t know how to improve. “Perfection” in my eyes. Quite impressed!
- I was very impressed by all the planning. The committee did an excellent job.
- Overall conference excellent. Organization of ThyCa volunteers, excellent, a joy to meet.
- This conference was well run.
- Speakers were generally excellent, conference was worthwhile. Committee members do an excellent job.
- Thanks.
- I’LL BE BACK!
- Very informative. Excellent info from medical people and great interactions with patients.
- Excellent!
- Outstanding seminar. Great job.
- This is one of the most interesting programs that I have ever been to. I have learned many things that will be of use for me to help my son.
- THE BEST THING THAT HAS HAPPENED TO ME SINCE BEING DIAGNOSED WITH MTC IS THIS SEMINAR!!!
- This is outstanding!! (Parent of a thyroid cancer survivor)
- Very informative
- Excellent!! A job done well!!
- I’m so impressed by the quality of the conference, the smooth flow of it. It’s obvious all the hard work that went into it and the number of really active volunteers. Thank you so much for all your work and dedication. I learned something vital from each session, and my overall understanding of my disease helps me align with my doctors. I’m also impressed by the willingness of the doctors to donate their time to ThyCa. You all deserve a hand and vacation! Thanks so much!
- Excellent -- amazed at the quality of speakers, their level of caring and overall quality of conference put together by volunteers at such an economical cost.
- Excellent conference. Impressed by fantastic speakers and the range of knowledge of all the survivors. A very uplifting experience. Thank you!
- Overall, I received some incredibly beneficial information here in the past 3 days and I am very grateful for this organization and the people in it. Thanks for everything!
- This has been a memorable experience that I’m glad we were able to attend—wish we could have attended more of the sessions, but had to make choices.
- Thanks to the committee for all their months of hard work – It was well organized and we hope to attend future conferences.
- Fantastic job. Thanks Gary, Megan and all.
- First time here and we found it was great! We had a wonderful realization that others understood us and we plan to come back next year!
- Great!!! Everyone is to be commended.
- Wonderful job.
- Outstanding conference and speakers.
- Very great conference. We are so pleased we came. Really enjoyed meeting all the people. They were so friendly and so supportive. We owe so much to Megan, Ric and all the great volunteers. ThyCa forever!!
- Excellent conference. Very good speakers, very good content, very well organized.
- Thank you so much!
- Conference was excellent. Extremely informative. We have learned to much!
- My compliments to the committee. This has been a very productive 3 days. I almost don’t want it to end. All of the sessions I attended were informative and worthwhile. It’s nice to see doctors in an informal situation. Especially nice to know they have a sense of humor. I look forward to the next conference.
- Y2K committee has done an excellent job.
- I learned more in these few days than I learned in the past 3 1/2 years. It was also comforting to meet other people with the same medical/social issues. I also appreciated the candor of the physicians. Excellent. Keep up the good work!
- I appreciated the doctors being accessible. Thank you for providing this much-needed conference for good information. This is especially critical when you don’t live in a Medical Center area.
- All of the doctors were wonderful and I appreciate their availability and ease in talking with everyone.
--Great!
--Magnificent conference! THANK YOU!!!

TOPIC AND PROGRAM COMMENTS/SUGGESTIONS
(Editor’s note: Some evaluation forms also had comments about individual speakers.)
--Repeat basics. There will always be new patients.
--The Ask a Doctor, Ask a ____, Sessions were EXCELLENT.
--Suggest more time with doctors and more question time.
--Hope we MTCs can be of more help to ThyCa in planning and promotion.
--More informal ask a doctor.
--If seminar about new drug or treatment such as Thyrogen, essential to have someone representing the other side, not just the side of the drug company.
--Some of the MD lectures were the perfect balance between good technical information and “plain English.” Others were having to adjust their lecture for the needs of the audience. I think the MDs that used the overhead and/or had handouts that helped us to follow did the best.
--Find out if people are being told the same protocol, such as low-iodine diet, not taking Synthroid with calcium, etc.
--LID roundtable earlier in the program rather than at the end.
--More double-session workshops like Van Nostrand’s.
--Appreciated Dr. Ain’s meeting informally to answer questions.
--Keep general sessions a little more general.
--Session to explain the differences in the types of thyroid cancer to help us understand what others are going through.
--Please encourage speakers to have handouts when possible.
--Shorter lectures, more Q & A, because attention spans shortened by hypo and treatments.
--Take specific personal questions that are off the topic somewhat at the end.
--Suggest session on immune system.
--Suggest session on doctor’s view of how to communicate.
--Suggest palliative care session.
--More sessions regarding psychological aspects of this cancer: normal emotions with cancer but guilt since this cancer normally doesn’t need chemo or “real” radiation, therefore feel uncomfortable participating in other cancer groups.
--Love the mental health aspect included in this year’s program, especially family of survivors.
--More interacting with caregivers, meeting regularly and/or exchanging e-mail.
--Insurance--separate roundtable for Medicare recipients.
--Insurance session more than once.
--Look Good, Feel Good session.
--Another session of a long term survivors’ perspective.
--Really appreciated the complementary sessions like Reiki, massage, art therapy, etc
--Suggest a lobbying day on Capitol Hill.
--2 1/2 days may be too much at one time.
--Not so early in September.
--Include library research resources (National Library of Medicine).
--Provide resources to help identify thyroid cancer expert doctors around the country.
--Good to have a large-group ingathering every morning.
--Liked wide selection of sessions.
--Time at end of each session to complete evaluation form.
--Evening: Have talks or unfacilitated sessions or specialty group discussions or something social or restaurant trip or sightseeing.
--Registration not in same room as speakers.
--Someone to greet and acclimate each speaker.
--Megan has a great voice and writes wonderful songs.

FACILITY, FOOD, AND OTHER COMMENTS/SUGGESTIONS
--Facility is great.
--Great facility. Convenient, comfortable, and affordable.
--10 votes for this site for next year’s conference.
--Great meeting location
--4-H facilities great Conveniently located for those of us not familiar with the DC area and coming from MD.
The room was very nice and the meals good.
--Meeting rooms generally comfortable with adequate sound and light
--Have the conference at a hotel
--Have better facility
--Have better food
--Program should have a page to write everyone’s name, e-mail address
--Distribute everyone’s name, e-mail address via e-mail message
--Find out during the conference who is from my area to facilitate easier meeting later.
--Name badge e-mail bigger
--Have continental breakfast choice because lunch and dinner meals were ample food for a day
--Have coffee and doughnuts at registration.
--Coffee
--Healthy snacks
--Hospitality room and activities
--Coffee, tea, soda provided at sessions, even if we pay for it, in addition to water
--Make mealtimes descriptions accurate
--Thanks for the goodie bag!
--Consider producing a CD of Megan’s songs.

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