## 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.<sub>SM</sub>, 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 <sub>SM</sub> 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.
- Financial Sponsors included the American Cancer Society, Genzyme Therapeutics, and Knoll Pharmaceuticals. Our computer corner was sponsored by Learning Tree International. Our flyer was designed by Just J Studios. Further donations came from AARP, Angelshare, CLG Promo, Dave Harris Copy/Print, Elison Communications, Foreign Candy Company, Half.com, Humana Press, Inc., Laclede, Inc., Montgomery County Volunteer Bureau, National Institutes of Health, Schoppy, Inc., SmithKlineBeecham, Treasure Chest Jewelers, Wilkes Technologies, and Writer's Center.
- 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 <sub>SM</sub> 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 <sub>SM</sub> Volunteer

11:00 a.m.—12 noon

131	Survivors' Roundtable: Papillary and Follicular
132	Survivors' Roundtable: Medullary
	Jeffrey Moley, M.D., Surgeon,
100	Washington University School of Medicine
133	Survivors' Roundtable: Anaplastic
12:15	—1:00 p.m.
	Lunch
	–2:30 p.m.
141	Research Update: Experimental Approaches
	to Aggressive and Dedifferentiated Thyroid Cancers
	Kenneth B. Ain, M.D., Endocrinologist,
	University of Kentucky Medical Center
142	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
143	Survivors' Families: Taking Care of Ourselves, Too
	Jon Mathis, ThyCa <sub>SM</sub> Volunteer
2:45–	–4:00 p.m.
151	Self-Care and Coping with Thyroid Cancer
	Over the Long Term: Roundtable
	Joy Paul, ThyCa <sub>SM</sub> Volunteer
152	Ask a Pharmacist
	Nayahamka McGriff, Phar.D.
	National Institutes of Health
153	Ask a Doctor
	Kenneth D. Burman, M.D., Endocrinologist,
	Washington Hospital Center
4:15–	–5:30 p.m.
161	Thyrogen Roundtable
	Kenneth D. Burman, M.D., Endocrinologist,
	Washington Hospital Center;
	Todd Foster, Thyrogen Marketing Manager, Genzyme Corporation
162	Medullary Issues
	Douglas Ball, M.D., Endocrinologist, The Johns Hopkins
	Medical Institutions
163	Massage Therapy: Caring Through Touch
	Carol and Greg Skolnik, Massage Therapists
164	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 <sub>SM</sub> Board Member
213	Other Complementary Approaches to Well-Being
215	Tai Chi
	Sue Gurland, L.Ac., Acupuncturist, ThyCa <sub>SM</sub> Volunteer
8: 45 a.m.	Daily Overview
	Megan Stendebach, Conference Coordinator
9:00—10:15	5 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 <sub>SM</sub> Volunteer;
	Nancy Harazduk, M.S., LICSW, Center for Mind-Body
	Medicine;
	Cheryl Hurwitz, LCSW-C, Body Psychotherapist,
	Musician, Performance and Recording Artist
223	Survivors' Families: Taking Care of Ourselves, Too
224	Diane Blake, ThyCa <sub>SM</sub> Volunteer
224	Survivorship Issues: Communicating with
	Our Doctors and Support Structure
225	Judith Bernardi, M.S.W., Ph.D., American Cancer Society
225	Reiki— Individual Sessions
10 20 11	Betty Solbjor, ThyCa <sub>SM</sub> Webmistress, ThyCa <sub>SM</sub> Board Member
10:30—11:4	
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
222	Medical Institutions
232	Ask a Pharmacist
222	Frank Puchino, Phar.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
224	Community Legal Clinic, George Washington University
234	Thyroid Cancer: A Long-Term Survivor's Perspective
	M. Sara Rosenthal, thyroid cancer survivor and author of
225	The Thyroid Sourcebook and The Thyroid Sourcebook for Women
235	Reiki— Individual Sessions
10.00	Betty Solbjor, ThyCa <sub>SM</sub> Webmistress, ThyCa <sub>SM</sub> Board Member
12:00 noon-	— 1:15 p.m.
	Lunch
	Health Care Forum

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<sub>SM</sub> Support Groups: Starting One, **Facilitating One** Ric Blake, ThyCa SM Support Groups Coordinator, ThyCa <sub>SM</sub> 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** Kristrinah 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** Kristrinah Talus-Ayala, B.F.A., M.S.Ed., LCPC, Director, Center for Creativity

U.S. Representative Connie Morella of Maryland

8:00 a.m.	Registration Desk Opens
311	Yoga Toroga Campama
	Teresa Campama,  Thy Co. Delayara Valley Support Group Facilitator
312	ThyCa <sub>SM</sub> Delaware Valley Support Group Facilitator <b>Reiki</b> — <b>Individual Sessions</b>
312	Betty Solbjor, ThyCa <sub>SM</sub> Webmistress
313	Other Complementary Approaches to Well-Being
314	Specialty Group Discussions
315	Tai Chi
	Sue Gurland, L.Ac., Acupuncturist, ThyCa <sub>SM</sub> Volunteer
8: 45 a.m.	Daily Overview and ThyCa Songs
ov 10 uv111	Megan Stendebach, Conference Coordinator
9:00—10:15 a	
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 <sub>SM</sub> Webmistress
325	Thyroid Basics: What Does Your Thyroid Gland
	Do for You?
	Arturo R. Rolla, M.D., Endocrinologist,
10.20 11.45	Beth Israel Deaconess Medical Center
10:30—11:45	
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,
332	Washington Hospital Center  Madullary Boundtable
332	Medullary Roundtable  Rebert F. Corol, M.D. Endominologist
	Robert F. Gagel, M.D., Endocrinologist,
333	University of Texas M.D. Anderson Cancer Center Workplace Issues and Employment Rights
<i>555</i>	Patricia Smith, Esq., Attorney
334	ThyCa <sub>SM</sub> : Getting Involved, Reaching Out,
	Spreading the Word
	Gary Bloom, ThyCa <sub>SM</sub> Board Chair
	J J

Reiki — Individual Sessions
Betty Solbjor, ThyCa <sub>SM</sub> Webmistress, ThyCa <sub>SM</sub> Board Member
Lunch and Conference Feedback.
Megan Stendebach, Conference Coordinator
5 p.m.
Research Update: The Low-Iodine Diet
Nancy Sebring, M.Ed., R.D., Clinical Research Dietitian,
National Institutes of Health
Humor and Healing
Andrea Cumberland, TC, Staff Chaplain,
Holy Cross Hospital
ThyCa Website Roundtable
Betty Solbjor, ThyCa <sub>SM</sub> Webmistress, ThyCa <sub>SM</sub> Board Member
AOL Thyroid Cancer Mutual Support Group
Roundtable
Karen Ferguson, ThyCa <sub>SM</sub> Board Member;
Donald Margouleff, M.D., Nuclear Medicine Physician,
North Shore University Hospital
o.m.
Roundtable and Closing Workshop

# $\label{eq:Gary Dionne, ThyCa} Gary \ Dionne, \ ThyCa_{SM} \ Volunteer \\ \textbf{B. EXHIBITORS}$

## **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

## ThyCa: Thyroid Cancer Survivors' Association, Inc. SM

P.O. Box 1545, NY, NY 10159-15451

Toll Free: 877-588-7904 Fax: 503-905-9725 <u>www.thyca.org</u>

thyca@thyca.org

#### C. DONORS

IN APPRECIATION FOR YOUR GENEROUS SUPPORT OF THYCA 2000

### FINANCIAL SPONSORS

American Cancer Society Genzyme Therapeutics Knoll Pharmaceutical Company

## CONFERENCE FLYER DESIGNER

Just J Studios, Leesburg, Virginia

#### COMPUTER CORNER SPONSOR

Learning Tree International, Reston, Virginia

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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.
- --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 mealtime descriptions accurate
- -- Thanks for the goodie bag!
- -- Consider producing a CD of Megan's songs.

**Updated 103100**