



ThyCa Journeys

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

Winter 2003-2004

Take Part in the Survey of Thyroid Cancer Patient Experiences

As part of ThyCa's continuing effort to increase knowledge about thyroid cancer, ThyCa has created a patient survey questionnaire to collect anonymous and confidential information about patients' experiences.

The survey was created by a ThyCa committee led by members of the ThyCa Publications Committee, in cooperation with other thyroid cancer survivors and medical experts. Survey funding came from the Advisory Board Foundation, Genzyme Therapeutics, and ThyCa: Thyroid Cancer Survivors' Association, Inc.

The survey's questions are designed to collect information from those who have had any of the forms of thyroid cancer, including papillary, follicular, medullary, anaplastic, and variants. The questions allow for the collection of specific, and anonymous, data.

The survey will provide health care professionals and patients with essential information on thyroid cancer treatments, management, and the experiences of thyroid cancer survivors. Results will be reviewed by thyroid cancer specialist physicians and published on the ThyCa web site.

Within the first 4 weeks, more than 800 people have already taken part. Thank you to everyone who's completed the survey. If you're a thyroid cancer survivor and haven't yet participated, you're invited, too. Visit our web site <www.thyca.org> and click on the link on the right side of the Home Page. Thank you!

Steven I. Sherman, M.D., New Member of our Medical Advisory Council

ThyCa is pleased to announce that Steven I. Sherman, M.D., has become a member of ThyCa's Medical Advisory Council. Dr. Sherman is an endocrinologist and thyroid cancer specialist at the University of Texas M.D. Anderson Cancer Center in Houston, Texas, where he joined the staff in 1993. —cont. on page 2

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Letter from the Editor

Dear Readers,

On a recent night, while indulging my insomnia, I decided to clean out the old e-mails cluttering up my e-mail account. I looked through the list of folders, trashing those that were empty. And then I realized what was taking up space in my almost-full account: the file named "ThyCa."

As I looked through the e-mails, dating back almost 4 years, I found the first e-mail I sent to Gary Bloom, the facilitator of my local support group. Even though Gary called me back and spent time answering my "newbie" questions, it still took months for me to screw up the courage and will to go to my first group meeting. From today's vantage point, I have no idea why it took me so long.

There are e-mails I sent to and received from my surgeon before and after my two operations. It still amazes me that she was willing to answer my questions electronically, and with such speed that I actually wondered how she managed to fit in surgeries between e-mails. There are e-mails from friends I made at my first ThyCa conference, e-mails sent to people on the listserv whose questions I was becoming knowledgeable and experienced enough to answer, and e-mails that led to my becoming happily associated with this newsletter.

Given the choice, I wouldn't have picked this experience. But the hundreds of e-mails are a not-unpleasant record of the last four years--and I have no intention of deleting them.

On a different note, I've heard from many people that the 6th annual ThyCa conference in Houston was a great success. Comments heard from participants included: "Excellent docs!" "Always such good sharing among participants." "Presenters were excellent." "Helpful... hopeful... THANK YOU" "This has been such a wonderful sharing of information. I look forward to next year's conference."

Along with presenting a survivor's story and news of recent ThyCa activities, articles in this newsletter are for those of you who, like me, were not able to make it to Houston, but want to get some of the conference's flavor, and for those of you who did attend, and want to recapture the weekend's wonderful experiences.

Be well,
Barbara Weinstein, Editor

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A 50-Year Survivor

by Jane Chady of Louisiana, with her mother Florence Roller
(From e-mails sent to ThyCa; reprinted with permission)

My mother, Florence Roller, is a 50-year survivor of thyroid cancer. She was diagnosed in October 1953 and was treated at the Mayo Clinic in Rochester, Minnesota. She had her 73rd birthday this past August.

When diagnosed with the cancer, she had a 3-month-old-son and an 18-month-old son. She went on to have three more children of which I am the youngest.... In the years after her treatment, she has had numerous (15) surgeries to remove swollen glands in the neck.

The first occurrence was in 1953. Then again in 1959, she was isolated in the hospital and was treated by ingesting radioactive iodine. She was in that room for 3 days. By this time she had had her third child. She went on to have two more children after being informed she would not be able to have more children.

Florence Roller adds, "I had a tracheotomy where a double tube is inserted in the neck to help breathing. The inner tube needed to be taken out and cleaned... The only way I could talk was to hold the tube shut with my finger so the air would come thru my mouth; otherwise I breathed thru the opening made with the tube in my neck.

So many things I remember.... the times I had to go without my thyroid pills to have checkups at Mayo with the gamma ray and gamma graff machines with radioactive iodine tracers which found whether more cancer cells were present. But the time they wanted to open me up like they do now for heart surgery I refused and took the next bus home. Lucky I was there myself so nobody could change my mind.

One time Grandpa Wandler went with me on the bus; another Anette Gresser went with me; also Fritize Feinginger one time, and a lot of times Dad drove....But carrying water in and out on the farm plus kids left me with a dropped shoulder.

Any way it's just part of how life is handed out and the way each person handles it. I'm lucky it was when I was young and tough. More memories than can be put in one letter."

Jane continues: When she was first diagnosed Mom and Dad owned a farm south of Dickinson, North Dakota. Having no insurance to cover medical bills, they had to sell the farm. They bought a house and had it moved to town. Dad took a job in construction and Mom took care of us with help from her mother. Mom went to work when I started first grade.

I don't know how they managed but they did. They paid all the medical bills over the years, sending sometimes as little as a \$10 payment. In 2000 they celebrated their 50th wedding anniversary and now in 2003 Mom celebrated her 50th cancer survivor anniversary.

I guess I'm sending this because I wanted to share this miracle story because that's what Mom is to me. Thank you for listening.

—Jane

Dr. Sherman— cont. from page 1

Dr. Sherman's presentations and question and answer sessions at this year's 6th International Thyroid Cancer Survivors' Conference focused on the management of papillary and follicular thyroid cancer and their variants, and on anaplastic thyroid cancer treatment and research.

He serves on the Executive Council and Education Committee of the American Thyroid Association, the Publications Committee of The Endocrine Society, the Board of Directors of the Texas Chapter of the American Association of Clinical Endocrinologists, and the Thyroid Cancer Panel of the National Comprehensive Cancer Network Guidelines Program.

A magna cum laude graduate of Harvard College, with a major in Biochemistry and Molecular Biology, Dr. Sherman graduated from Johns Hopkins School of Medicine in 1985. He completed his postgraduate internship, residency, and clinical fellowship training at Johns Hopkins Hospital in Baltimore, Maryland. He is a frequent presenter at meetings of professional organizations. He serves on the editorial board of the "Journal of Clinical Endocrinology and Metabolism" and the "National Comprehensive Cancer Network Journal."

The ThyCa Medical Advisory Council provides valuable counsel and supports ThyCa's goals in education, treatment, and research.

About This Newsletter and ThyCa.

This free newsletter is posted on our web site and distributed by e-mail. The articles in this newsletter represent the opinions of their authors and are not official positions of ThyCa: Thyroid Cancer Survivors' Association, Inc. The articles by laypeople do not offer medical advice, as the authors are not doctors and have no medical training. If you have medical questions, please consult with your physician.

ThyCa: Thyroid Cancer Survivors' Association, Inc. <www.thyca.org> is an all-volunteer nonprofit 501(c)(3) service organization providing support, education, and communication for thyroid cancer survivors, family members and friends.

We welcome new volunteers and members at any time.

ThyCa News Nuggets

Cookbook's 4th Edition. We're proud to announce the expanded 4th edition of our free ThyCa Low Iodine Cookbook. With 43 pages and more than 120 recipes for appetizers, soups, breads, main courses, and desserts, the cookbook is one of our most popular items. Leah Guljord, ThyCa's Assistant Board Chair and Support Groups Coordinator, is the editor, and 36 other thyroid cancer survivors donated their own original recipes. Thank you! Free for downloading from ThyCa's website, the cookbook's recipes are sure to make even the most hypothyroid mouth water.

New Local Support Groups. Our two newest local support groups will start meeting in January in Grand Rapids, Michigan, and in Kansas City, Missouri. Mary Van Diepenbos and Debbie Parnacott are the facilitators of these new groups. If you live in one of these areas, plan to attend. For details, see the ThyCa Support Groups section of our web site.

E-mail Support Groups. ThyCa's largest e-mail support group now has more than 1,500 participants! Visit the Support Groups section of the ThyCa web site to join an e-mail group for your situation.

Book Donation. ThyCa thanks Sheldon Rubinfeld, M.D., for his generous donation of a large number of copies of his book, *Could It Be My Thyroid?* to all of ThyCa's local support group facilitators, support services volunteers, and conference attendees. Thank you also, Dr. Rubinfeld, for the excerpts being published on ThyCa's web site.

ATA Honor. Thank you to the American Thyroid Association, which honored ThyCa during its September 2003 Annual Meeting. The award was given in recognition of ThyCa's status as the first-ever patient organization to fund thyroid cancer research. ThyCa also appreciates ATA's initiation and involvement in an Alliance of Thyroid Patient Groups, in which ThyCa is participating. Leah Guljord, ThyCa Board Member, represented ThyCa at the ATA meeting and the patient education forum on thyroid disease co-sponsored by ThyCa during the meeting.

Grant from Metlife. ThyCa would like to extend our thanks to Metlife for giving a grant to ThyCa for our support services and outreach efforts. The grant is in recognition of the volunteer service of Sherri Eccleston, ThyCa Rhode Island Support Group facilitator, in support of thyroid cancer survivors and families. We are grateful to Metlife for their generosity in supporting ThyCa.

Radio Meeting. Our thanks to the Houston Area Radio Stations for inviting to give a presentation about our support services and resources at its December meeting of 15 radio stations, and to our medical advisor Steven I. Sherman, M.D., for representing ThyCa.

Thyroid Cancer Research Grant. The American Thyroid Association has announced, on its web site and in its membership newsletter, ThyCa's 2004 grant for thyroid cancer research. Proposals for the ThyCa-sponsored grant are being solicited and are due at the American Thyroid Association by January 31, 2004. ATA's review panel will rank the proposals and ask authors of selected proposals to submit full grant applications, from which the grant recipient will be selected. We greatly appreciate the generous donations to ThyCa that make our grant possible, and thank the ATA for its expertise in managing the grant review and selection process.

Radiation Guidelines. The Society of Nuclear Medicine has provided ThyCa with information, now posted on our website <www.thyca.org>, on procedures to follow at home after radioactive iodine treatment. ThyCa thanks the Society of Nuclear Medicine for its assistance in further educating survivors and caregivers.

Thank You. ThyCa expresses our gratitude to our Board Members Emeritus: Ric Blake, Melanie Reiser, Megan Stendebach, and Mary Rose Weckerle. Their wonderful contributions to ThyCa's board and their other efforts on ThyCa's behalf are greatly appreciated. We look forward to their continuing participation in our support services.

Marathon Runner. David Sanders, son of Dave Sanders, a Medullary Thyroid Cancer Survivor, ran in the White Rock Marathon in Dallas, Texas, on December 14, 2003. David dedicated his Marathon Run to ThyCa's Medullary Thyroid Cancer Research Fund. Congratulations and thank you, David, and to everyone who supported your wonderful run for thyroid cancer research!

Presentation. Dr. Kenneth Burman, Director of Endocrinology at the Washington Hospital Center, spoke to the Washington, D.C. ThyCa support group in Silver Spring, Maryland, on November 15, 2003. More than 40 thyroid cancer survivors and caregivers were in attendance as Dr. Burman shared information about thyroid cancer and answered questions. Thank you, Dr. Burman.

Web Site Addition. Our web site <www.thyca.org> has a fresh addition to the Newly Diagnosed page. The Thyroid Cancer Resource List is a one-stop listing of thyroid organizations, conference and workshop information, support groups, reading material, and key Internet resources related to thyroid cancer. Check out and download our Resource List at

http://www.thyca.org/newly_diagnosed.htm

Free Booklet on Fine Needle Aspiration Now in Spanish, Too

We're excited to report that Yolanda C. Oertel, M.D., Pathologist and Director of the Fine Needle Aspiration Service at the Washington Hospital Center, Washington, D.C., has developed a Spanish translation of her booklet titled *Fine Needle Aspiration of the Thyroid: The Patient's Guide*.

Dr. Oertel is one of ThyCa's medical advisors and has spoken at our conferences and workshops.

In more than 50 questions and answers, this informative booklet covers key information helpful to patients undergoing fine needle aspiration to determine the nature of a nodule.

Developed by Dr. Oertel and several Spanish-speaking colleagues, the new booklet has the same questions and answers as the English original. Dr. Oertel also has generously donated a large number of copies to ThyCa, and has allowed the posting of excerpts on the ThyCa web site. The full text will also appear as one chapter in the forthcoming book *Thyroid Cancer: A Guide for Patients*, edited by Douglas Van Nostrand, M.D., and others and with chapters by 14 physicians.

The English-language original of the booklet on Fine Needle Aspiration is available by sending a self-addressed, stamped envelope with 2 ounces of postage to the ThyCa volunteer listed at the end of the excerpt on our web site.

We appreciate and thank Dr. Oertel for her wonderful support of patients!

Have You Checked Out the ThyCa Web Site Lately?



Our web site <www.thyca.org> is chock full of information for newbies, long term survivors, and caregivers. Our low-iodine cookbook is available free for downloading and provides recipes for even the most hypothyroid chef. The humor section provides jokes and goofy songs to bring a smile to anyone's face. Information about testing, thyroid cancer variants, thyroid cancer research, and clinical trials will assist any patient looking to improve his or her knowledge.

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

ThyCa's 6th International Thyroid Cancer Survivors' Conference

ThyCa: Thyroid Cancer Survivors' Association, Inc. held its 6th International Thyroid Cancer Survivors' Conference in Houston, Texas on October 24-26, 2003.

This educational and supportive weekend brought together more than 340 participants from a new record total of 32 states, 2 Canadian provinces, and the United Kingdom.

Our participants included survivors of every type of thyroid cancer (papillary, follicular, medullary, anaplastic, and variants), from those newly diagnosed and awaiting surgery to survivors of more than 30 years, as well as caregivers and friends. They ranged in age from children under age 10 to seniors.

Our 18 physician speakers included specialists in endocrinology, surgery, pathology, nuclear medicine, and medical oncology from M.D. Anderson Cancer Center, Johns Hopkins Medical Institutions, Washington School of Medicine, Baylor College of Medicine, University of Cincinnati Medical School, and other centers. We greatly appreciate their sharing of their expertise. Our web site's Conference section has a complete list of the speakers.

Speakers in the more than 90 sessions over the three days also included research nurses, a dentist, a pharmacist, mental health professionals, a chaplain, an attorney specializing in employment and workplace issues, specialists in complementary approaches and coping skills for well-being, and many long-term survivors as well as caregivers. We have notes from conference presentations and plan to add more information from the conference to our web site in the coming months.

Dozens of wonderful volunteers, including many who were unable to attend, helped with the conference preparations and during the weekend itself.

Thank you to everyone!

Dental Issues: A New Topic at the 2003 Conference

For the first time in the history of ThyCa's conferences, participants heard from a dental expert about dental issues associated with thyroid cancer, particularly the effects of radioactive iodine on oral health.

Mark S. Chambers, M.S., D.M.D., Dentist and Oral Oncologist at the University of Texas M.D. Anderson Cancer Center in Houston, shared information about the protocol followed at M.D. Anderson, one of the nation's premier thyroid cancer treatment centers.

At M.D. Anderson, patients receive a dental cleaning before treatment for all forms of thyroid cancer.

Also important is follow-up care after radioiodine treatment, to neutralize the changed acidity of saliva.

Dr. Chambers told participants that upon noticing any change in taste or saliva, they should stop using commercial toothpastes and mouthwashes and switch to ultra-soft toothpastes and mouthwashes without alcohol, phenol or whitening agents.

A good alternative to commercial products is baking soda for use as a scrubbing agent and baking soda mixed with water as mouthwash—to be used 4-5 times daily. (For mouthwash, Dr. Chambers suggested mixing one heaping teaspoon with 10 ounces of water.)

Dr. Chambers also stressed the importance of flossing daily!

More information on this topic will be posted on the ThyCa website at www.thyca.org.

ThyCa's 2nd Annual Dinner and Research Benefit Auction

One of the highlights of the ThyCa's conference weekend in Houston was the 2nd annual dinner and fundraising auction, kicked off by a welcoming video-message from Catherine Bell, thyroid cancer survivor and star of TV's hit series JAG. The dinner and auction were attended by almost 200 participants, who bid on a wide array of donated items including all kinds of food, clothing, and jewelry, digital cameras, and a variety of delightful gift baskets on regional and state themes, created by volunteers in local ThyCa support groups across the United States.

The evening, which was organized by ThyCa Fundraising and Event Chair Joni Eskenazi from Seattle, Washington, began with a welcome from ThyCa Board Chair Gary Bloom of Olney, Maryland.

Moving and inspirational speeches were given by Jeffrey Moley, M.D., Surgeon at Washington University School of Medicine in St. Louis, Missouri, and by ThyCa volunteers Pattie Scott of Colorado, who lost her husband, David, to anaplastic thyroid cancer, and Tina Anders, medullary thyroid cancer survivor and ThyCa Denver support group facilitator. Megan Stendebach, ThyCa member from San Antonio, Texas, and Conference Coordinator, gave a singing and slide presentation as well as a tribute to the volunteers who made September's Benefit Golf Tournament such a success.

Thanks to the generosity of our supporters, we're delighted to announce that the fundraising dinner and auction raised even more than last year to help us build our Research Funds as well as support another ThyCa grant for thyroid cancer research in 2004.

Save the Date:
ThyCa's 7th International Conference
October 22-24, 2004

Just when you thought it couldn't get any better – ThyCa's heading for the Windy City!

ThyCa's 7th International Conference will be held October 22-24, 2004 in Chicago, Illinois, at the Hyatt Deerfield Hotel.

For more information, check out the conference flyer already posted on the ThyCa web site. You are welcome to download and print it out for posting and sharing with others. We'll add further details as our plans develop.

Please help us spread the word about the conference—tell your physician, relatives, and friends about the conference. And if you'd like to volunteer to help with the planning or at the conference itself, please e-mail our Conference Planning Team at conference@thyca.org

An Open Invitation from ThyCa

ThyCa invites thyroid cancer survivors, families, and friends to tell your friends and relatives about our free year-round support services and publications, including our award-winning educational web site, as well as about next year's conference and free spring workshops.

If you'd like to help us sustain and strengthen our free support services and educational resources, we invite you to visit our web site to find out how How to Help through membership, donations, and volunteering.

Thank you very much for your support.

