



ThyCa: Thyroid Cancer Survivors' Association, Inc.SM

An all-volunteer non-profit 501 (c)(3) organization of thyroid cancer survivors, family members, and health professionals, dedicated to support, communication, and education for thyroid cancer survivors, their families, and friends • P.O. Box 1545, New York, NY 10159-1545
thyca@thyca.org www.thyca.org Toll Free 1-877-588-7904

ThyCa Journeys

Spring 2002

*Support and communication for thyroid cancer survivors and families.
A free publication of ThyCa: Thyroid Cancer Survivors' Association, Inc.*

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Letter from the Editor

Welcome to the 3rd issue of Journeys, the free online newsletter of ThyCa: Thyroid Cancer Survivors' Association. This edition is chock full of information about ThyCa members, regional workshops, the October 2002 conference in Los Angeles, new e-mail support groups, and much more. As always, we hope you enjoy reading about the latest ThyCa happenings. If you have any comments about this newsletter or suggested topics for our next edition, please feel free to pass them along. This is YOUR newsletter!

Barbara Weinstein
Editor-in-Chief
newsletter@thyca.org

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Profile of a ThyCa Member and Volunteer: Spotlight on Beth Scott



by Barbara Weinstein

(Note: In the first of what will be a regular series featuring a ThyCa member, Journeys profiles Beth Scott, gold-medal winning Paralympic athlete and thyroid cancer survivor.)

Born with Ocular Albinism and Nystagmus, an uncorrectable eye disability that gave her 20/200 vision, Beth began dreaming of an Olympic career in competitive swimming after watching the 1984 Games on television.

"I knew then that I wanted to be an Olympian. I just had no idea how much hard work it would take to get there," she says.

The attraction to the water was powerful. Beth recalls feeling free of the obstacles of everyday life while swimming. Her determination and hard work paid off when she received a full athletic scholarship to Ball State University in Muncie, Indiana.

At age 18, Beth was ranked sixth in the nation in the 200-meter butterfly event. That same year, she placed third at the World Championships in the same event. Throughout this time, Beth continued to compete at events for athletes with and without disabilities.

While only 10 percent of her competitions were events for people with disabilities, in 1992 Beth traveled to Barcelona, Spain, to compete in her first Paralympic Games. Although sometimes confused with the Special Olympics that feature individuals with mental disabilities, the Paralympic Games differ in that the athletes have only physical disabilities. The Paralympic Games are held every four years and are the second-largest sporting event in the world after the Olympics. Paralympians stay in the same village and compete in the same venues as the non-disabled athletes. In Barcelona, Beth won seven gold medals and broke seven World and American records.

Four years later, in 1996, Beth won one gold, one silver, and four bronze medals at the Atlanta Paralympic Games. And at the 2000 Games in Sydney, Australia, Beth capped her Paralympic career by bringing home two gold medals, as well as a silver and bronze medal.

Several months after the Sydney games, Beth began to experience pain in her neck. She had been living and training at the Colorado Springs Olympic Training Center. But Beth was spending the Christmas holiday at home with her family in Maryland when she was diagnosed with papillary thyroid cancer. The diagnosis forced her to alter her plans to begin a post-Olympic life in Colorado.

With weeks of her diagnosis, Beth underwent a total thyroidectomy and later, a round of radioiodine therapy. While Beth was going through treatment, her endocrinologist told her about the support services of ThyCa: Thyroid Cancer Survivors' Association. Since 2001, Beth has been a member of the ThyCa support group in Silver Spring, Maryland.

What does Beth feel she gets from belonging to ThyCa?

"I have gained an education and a better understanding of thyroid cancer and my own treatments. What is so great about ThyCa is that it not only meets your support needs (the warm and fuzzy); they also provide their members with information and a greater understanding of their disease."

Beth is helping other ThyCa volunteers raise awareness about thyroid cancer, the importance of early detection, appropriate treatment, and lifelong monitoring, and the benefits of the free support services available from ThyCa.

Although Beth retired from competitive swimming after the Sydney Paralympics, she continues to be involved in the Olympic movement. She is a member of the Board of Directors and Athlete Advisory Committee that is trying to bring the Olympic and Paralympic Games to the Washington, D.C. metropolitan area in 2012. She says she is optimistic about the area's ability to host the Games.

And while having had thyroid cancer was not the next challenge she would have chosen after her Olympic career, Beth says that the experience has not been entirely negative.

"In life there are ups and downs, challenges, that we have to meet. I am one of those kinds of people, who believes that something good will always come from something bad. I try to find the positive in the negative. It may sound a bit like a cliché, but it works for me."

So, where does Beth see herself in ten years?

"Healthy and happy living and working in beautiful Colorado Springs. Leading a ThyCa support group. And I better be married and starting a family by then, too, so if anyone is looking for a SWF without a thyroid, you need not look any further."

ThyCa To Host Free Spring Workshops

This spring, ThyCa is hosting three regional survivors' workshops to be held in Fairfax, Virginia; Warwick, Rhode Island; and New York, New York. The purpose of the day-long workshops is to allow participants to meet with health care professionals and share information, as well as to meet and share with other survivors and caregivers.

The Capital Area Thyroid Cancer Survivors' Workshop, to be held Saturday, April 27, from 9 a.m. to 3 p.m., will take place at the Inova Health System's Life with Cancer Family Center. The Center is located at 2832 Juniper Street in Fairfax/Merrifield Virginia. Featured speakers are:

-**Lisa M. Boyle, M.D.**, Endocrine Surgeon, Washington Hospital Center, Washington, D.C.

-**Dodi Christiano, M.A.**, Oncology Counselor, Inova Fairfax Hospital, Fairfax, Virginia

-**Frank R. Crantz, M.D.**, Endocrinologist, McLean, Virginia

-**Yolanda Oertel, M.D.**, Pathologist, Washington Hospital Center, Washington, D.C.

-**Matthew D. Ringel, M.D.**, Endocrinologist, Washington Hospital Center, Washington, D.C.

-**Karen Smyers**, National and World Champion Triathlete.

In addition, thyroid cancer survivors will speak of their experiences.

The New England Thyroid Cancer Survivors' Workshop, to be held on Saturday, May 18 from 9:30 a.m. to 3:30 p.m., will take place at the Kent County Memorial Hospital Auditorium, 455 Tollgate Road, Warwick, Rhode Island. Featured physicians are:

-**Stephanie Lee, M.D., Ph.D.**, Endocrinologist, Boston Medical Center, Boston, MA

-**Arturo Rolla, M.D.**, Endocrinologist, Beth Israel Deaconess Medical Center, Boston, MA

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

The New York Thyroid Cancer Survivor's Workshop, will take place at Beth Israel Medical Center, with the date and time to be announced on the ThyCa web site. Featured physician is:

-**Roy Sessions, M.D.**, Otolaryngologist, Beth Israel Medical Center, New York, NY

These events are free and open to everyone. For additional information about the workshops, please see the Conferences / Workshops page of the ThyCa web site, www.thyca.org

ThyCa Web Site Gets a Facelift



Have you checked out the ThyCa web site, www.thyca.org, lately? Frequent visitors to the site have noticed its new and improved look—courtesy of webmistress Betty Solbjor.

Betty was one of the original ThyCa founders. She used her web skills to create the ThyCa web site starting in 1998. As Betty says, "The goal of the web site is to educate patients and family members about thyroid cancer."

The information on the web site is designed to serve individuals and families throughout all stages of diagnosis, treatment, recovery, and survivorship. For the newly diagnosed, there is a primer on thyroid cancer and suggested questions to ask of doctors. For individuals going through treatment or follow-up, the web site has the popular free ThyCa Low Iodine Diet Cookbook, with recipes to tempt the most hypothyroid patients. The web site also provides information about local support groups, the annual ThyCa Conference, and links to the many online support groups.

In addition, visitors to the site will also notice two new additions to the list of e-mail support groups. In recognition of the diverse thyroid cancer survivor community, there is now an e-mail support group. In addition, visitors to the site will also notice two new additions to the list of e-mail support groups. In recognition of the diverse thyroid cancer survivor community, there is now an e-mail support group.

dedicated to the needs and concerns of caregivers. The group provides a support forum for family members and friends of people dealing with thyroid cancer.

As well, there is a new e-mail support group dedicated to the needs and concerns of long-term survivors. The group provides a forum for survivors who are past the initial years of treatment and follow-up for thyroid cancer.

Thanks to the web site, "No thyroid cancer patient needs to feel that he or she is the only one dealing with this," says Betty.

Although anyone can ask to have information posted on the site, all medical content is reviewed and approved by the ThyCa Medical Advisory Council to ensure accuracy. Updates are made as frequently as necessary and sometimes as often as twice a week. According to Betty, "When a new support group is formed, or new information becomes available, the information is sent to me, and I upload it as soon as I can."

So, what's the web site's most important function?

Replies Betty, "Not everyone has access [to physicians] or their physicians may not have the best knowledge of how to treat thyroid cancer, and I feel it is of the utmost importance that patients arm themselves with solid information so that they can be their own advocate and receive proper treatment."

ThyCa Introduces Tribute Gift Cards: *A New Way To Help in the Fight Against Thyroid Cancer*

To provide ThyCa members and supporters with a way to honor, memorialize, or congratulate friends and family, ThyCa has created Tribute Gift Cards.

The Cards are available for all occasions—birth announcements, birthdays, anniversaries, graduation, congratulations, get-well messages, sympathy and memorials, and more. The beautifully designed cards are sent to the recipient you designate, along with a handwritten message and a note that you are the donor.

Donations of any amount received by ThyCa are used to fund research into thyroid cancer. For each person you wish to honor, please fill out the Tribute Gift Card Donation Form available on the ThyCa web site, www.thyca.org.

In order to ensure timely receipt, the form may be sent well in advance of when you wish the card to be sent. The Donation Form may be mailed, along with your check to ThyCa Tribute Gift Card, P.O. Box 1545, New York, NY 10159-1545. The form may also be emailed to Tribute-gift@thyca.org

By honoring a dear friend, remembering a loved one, or marking a special occasion, you will be helping to fund thyroid cancer research and fight this disease that has touched our lives so profoundly. Together we can reach our ultimate goal of curing all thyroid cancers.



Potassium Iodide and the Thyroid Gland

(Editor's Note: The information contained in this article is intended for educational purposes only. It is not intended, nor should it be interpreted, as medical advice or directions of any kind. Any person viewing this information is strongly advised to consult their own medical doctor(s) for all matters involving their health and medical care.)

On March 28, 1979, equipment failure and human error led to a partial core meltdown at the Three Mile Island nuclear reactor in Middletown, Pennsylvania.

Although the incident did not cause widespread radiation exposure, it prompted the government to seek new ways to protect people living near nuclear reactors from radiation poisoning in the event of another accident. The distribution of potassium iodide was one such protective method. Also known by its symbol on the periodic table of elements, KI, potassium iodide protects the thyroid gland against radiation exposure and the thyroid cancer it can cause.

In the aftermath of the September 11, 2001, tragedies, experts are again turning to KI. As of March 20, 2002, eleven states (Alabama, Arizona, Connecticut, Delaware, Florida, Maryland, Massachusetts, New Hampshire, New Jersey, New York and Vermont) had requested and/or received KI tablets from the Nuclear Regulatory Commission, in quantities great enough for distribution to all individuals living within a 10 mile radius of a nuclear power plant.

Journeys asked Kenneth D. Burman, M.D., an endocrinologist at Washington Hospital Center in Washington, D.C. and a member of ThyCa's Medical Advisory Council, what thyroid cancer survivors and their families and friends should know about KI.

Journeys: What is KI?

Dr. Burman: Potassium Iodide (KI) is simply a nonradioactive iodine that is similar or identical to iodine found in many foods.

Journeys: How does KI protect the thyroid of a healthy individual in the event of radiation exposure?

Dr. Burman: When this iodine is given in sufficiently large doses, it can block or inhibit the uptake of radioactive iodine into the thyroid gland. In general terms, about 500 micrograms of regular nonradioactive iodine is ingested daily in an average North American diet. Potassium iodine solution contains an enormous amount of iodine, usually greater than 100,000 micrograms daily. This enormous amount of iodine is preferentially taken up by the thyroid gland and less radioactive iodine would then be taken up. The mechanism by which this happens is simply dilution—there are so many nonradioactive iodine molecules available that the chance of a radioactive iodine molecule is taken up is markedly reduced.

Journeys: Is KI 100% effective in protecting the thyroid from radiation exposure?

Dr. Burman: It is unknown if KI is 100% effective in decreasing radioactive iodine exposure to the thyroid gland. Certainly it decreases the chance a radioactive iodine molecule would be trapped by the thyroid gland.

Potassium Iodide and the Thyroid Gland— *Continued from page 4*

Journeys: In what real-world cases has KI been used?

Dr. Burman: KI was used in Poland to decrease isotope uptake by the thyroid gland following the Chernobyl accident, and it seems that it indeed was effective in decreasing the subsequent chance of patients getting thyroid cancer. This, of course, was not a controlled study.

Journeys: Is KI equally beneficial for children and adults?

Dr. Burman: It is unknown if the benefits of KI would be similar in adults and children, but it is suspected they would be comparable. The doses of KI given to children are less than adults.

Journeys: What would be the benefits of KI for someone without a thyroid who has been exposed to harmful radiation?

Dr. Burman: Since someone who has had thyroid cancer would likely have had a thyroidectomy as well as radioactive iodine treatment, they would not be expected to have residual thyroid tissue. Therefore, even if there was a nuclear accident with release of radioactive iodine, they would not be expected to trap this iodine. As a result, there is no expectation that they would suffer any thyroid consequences. On the other hand, radioactive iodine is trapped by salivary glands

and other tissues, to a small extent, and although I have not read anything scientific on this topic, it seems reasonable to me for even thyroid cancer patients to consider taking KI in the event of a nuclear accident. This topic needs further evaluation and should be discussed by the patient with their physicians.

Journeys: Are there any side effects to KI?

Dr. Burman: Some patients are allergic to KI and most likely will have a skin rash although very rarely more serious adverse effects can occur. If a patient has a thyroid gland, KI can rarely cause hyper or hypothyroidism. A history of allergy to shellfish or radiocontrast dye does not necessarily indicate an adverse reaction to iodine and these issues should be discussed with each individual physician.

Journeys: Does KI protect any other part of the body besides the thyroid from radiation exposure?

Dr. Burman: The most important known effect of taking KI is protecting against thyroid uptake of radioactive iodine. It will not prevent exposure or risk for subsequent significant medical problems such as leukemia. It may have some minor effect on decreasing salivary gland uptake (and perhaps even breast tissue uptake in lactating women) of radioactive iodine, but the long term beneficial effects in these areas are unknown.

Dinner/Auction to Benefit Thyroid Cancer Research *Friday, October 11 at 7 p.m.*

We are pleased to announce that ThyCa: Thyroid Cancer Survivors' Association Inc., has initiated a major fundraising campaign for urgently needed research on all types of Thyroid Cancer.

We invite you to join us in honoring our Medical Advisory Council at our Fundraising Dinner/Grand Silent Auction on Friday October 11, 2002, from 7 to 10 p.m. at the Los Angeles Athletic Club (LAAC), our conference headquarters. You will surely be delighted by the surprise entertainment package we have planned for your enjoyment. The cost for the dinner event is \$60 per person payable by credit card or check to ThyCa; however, your generosity beyond that would be greatly appreciated. Due to the generosity of the LAAC and our dedicated core of volunteers, all net proceeds raised at this event will go directly to support our Research efforts.

Please sign up through the form on our web site, and help support our efforts to "STRIKE OUT THYROID CANCER".

—Joann Chaikin Eskenazi, jeskenazi@thyca.org, *ThyCa Fundraising and Event Chairman*

More About This Newsletter and ThyCa

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. Articles by physicians are educational and not intended to offer medical advice, as physicians cannot diagnose through the Internet. 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 advised by nationally recognized thyroid cancer specialists and dedicated to support, education, and communication for thyroid cancer survivors, their families, and friends. Throughout the year ThyCa offers free resources, including education through the web site, our low-iodine cookbook downloadable from the web site, this newsletter, several e-mail support groups, local support groups coast to coast, the person-to-person network for one-to-one support, newsletters, and the survivors' toll-free telephone number.



ThyCa's 2002 Annual Conference: An L.A. Story

On October 11-13 2002, hundreds of thyroid cancer survivors, caregivers, and leading medical professionals will converge on downtown Los Angeles to learn from one another.

The event is the Fifth International Thyroid Cancer Survivors' Conference, sponsored by ThyCa: Thyroid Cancer Survivors' Association, Inc. The conference takes place at a beautiful private club and conference facility, the Los Angeles Athletic Club at 431 West 7th Street.

We're delighted to announce the confirmed speakers to date:

Kenneth B. Ain, M.D., Endocrinologist, University of Kentucky Medical Center, Lexington, KY
Diane Blake, M.A., ThyCa Volunteer, NH
Ric Blake, ThyCa Volunteer, NH
Gary Bloom, ThyCa Volunteer, MD
Gregory Brent, M.D., Endocrinologist, UCLA School of Medicine / West Los Angeles VA, Los Angeles, CA
Teresa Campama, Yoga Instructor, NJ
Inder Chopra, M.D., Endocrinologist, UCLA School of Medicine, Los Angeles, CA
Gary Clayman, D.D.S., M.D., Surgeon, University of Texas M.D. Anderson Cancer Center, Houston, TX
David Cooper, M.D., Endocrinologist, Sinai Hospital of Baltimore, Baltimore, MD; Secretary, American Thyroid Association
Douglas Evans, M.D., Surgeon, University of Texas M.D. Anderson Cancer Center, Houston, TX
Alan P. Farwell, M.D., Endocrinologist, UMass Memorial Medical Center, Worcester, MA; Chair, Patient Education and Advocacy Committee, American Thyroid Association
Karen Ferguson, Founder (1995) and Co-Facilitator, AOL Thyroid Cancer Mutual Support Group, NC
Robert F. Gagel, M.D., Endocrinologist, University of Texas, M.D. Anderson Cancer Center, Houston, TX
Leah Guljord, Coordinator, ThyCa Support Groups and Editor, *ThyCa Low Iodine Cookbook*, FL
Bryan Haugen, M.D., Endocrinologist, University of Colorado Health Sciences Center, Denver, CO
Jerome Hershman, M.D., Endocrinologist, UCLA School of Medicine, Los Angeles, CA
Mark Hiepler, Esq., Insurance Attorney, Hiepler & Hiepler, Oxnard, CA
Elizabeth Irion, Co-Facilitator, AOL Thyroid Cancer Mutual Support Group, PA
Mark Irion, ThyCa Volunteer, PA
Richard Kloos, M.D., Endocrinologist, Ohio State University, Columbus, OH
Marvin E. Krakow, Esq., Attorney, Employment Issues, Los Angeles, CA
P. Reed Larsen, M.D., Endocrinologist, Brigham and Women's Hospital, Boston, MA
Stephanie Lee, M.D., Ph.D., Endocrinologist, Boston Medical Center, Boston, MA

Susan Mandel, M.D., Endocrinologist, Hospital of the University of Pennsylvania, Philadelphia, PA
Donald Margouleff, M.D., Chief of Nuclear Medicine, North Shore University Hospital, Manhasset, NY
Yolanda Oertel, M.D., Pathologist, Washington Hospital Center, Washington, DC
Greg Randolph, M.D., Otolaryngologist, Massachusetts Eye and Ear Infirmary, Boston, MA
Vera Ray, Facilitator, ThyCa Medullary Thyroid Cancer E-Mail Support Group, GA
Matthew D. Ringel, M.D., Endocrinologist, Washington Hospital Center, Washington, DC
Arturo R. Rolla, M.D., Endocrinologist, Beth Israel Deaconess Medical Center, Boston, MA
Nicholas J. Sarlis, M.D., Ph.D., Endocrinologist, National Institutes of Health, Bethesda, MD
Pam Schultz, R.N., M.S., Program Director for Endocrinology, University of Texas, M.D. Anderson Cancer Center, Houston, TX
Rena Vassilpoulou-Sellin, M.D., Endocrinologist, University of Texas, M.D. Anderson Cancer Center, Houston, TX
Steven I. Sherman, M.D., Endocrinologist, University of Texas, M.D. Anderson Cancer Center, Houston, TX
Peter Singer, M.D., Endocrinologist, USC Ambulatory Care Health Center, Los Angeles, CA; President-Elect, American Thyroid Association
Karen Smyers, National and World Champion Triathlete, MA
Betty Solbjor, ThyCa Webmistress and Reiki Practitioner, MA
Carole Spencer, Ph.D., F.A.C.B., Professor of Medicine, University of Southern California, Los Angeles, CA; President, American Thyroid Association
Megan Stendebach, Conference Coordinator and Thyroid Cancer Song Composer, TX
R. Michael Tuttle, M.D., Endocrinologist, Memorial Sloan-Kettering Cancer Center, New York, NY
Leonard Wartofsky, M.D., Endocrinologist, Washington Hospital Center, Washington, DC
Kevin Williams, Clinical Coordinator, University of Kentucky Medical Center, Lexington, KY
Lawrence Wood, M.D., Endocrinologist, Massachusetts General Hospital, Boston, MA

Conference sessions will cover topics important to attendees at all stages of testing, treatment, and follow-up. Sessions geared toward the needs of caregivers will also be held. And as in past years, the highlight of the Conference will be the social interaction between survivors, many of whom have never before met another thyroid cancer patient. We look forward to seeing you there. Hope you'll come to the Research Fund Benefit Dinner and Silent Auction, too!

Visit ThyCa's Web Site for the registration form, transportation and lodging details, and updates on the Benefit Dinner and Silent Auction.

**10th National Graves'
Disease Patient and Family
Conference**
October 11-13, 2002
Los Angeles, CA
www.ngdf.org

Help Us Help Each Other

We want your comments on this newsletter! Do you like it? What would you like us to print? Send your comments to newsletter@thyca.org or ThyCa: Thyroid Cancer Survivors' Association, Inc. P.O. Box 1545, New York, NY 10159-1545