

# ThyCa: Thyroid Cancer Survivors' Association, Inc.

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## Annual Report for 2014



### Organization Overview

Begun in 1995, ThyCa: Thyroid Cancer Survivors' Association, Inc. (ThyCa) <[www.thyca.org](http://www.thyca.org)> is a non-profit 501(c)(3) organization of thyroid cancer survivors, family members, and health care professionals. ThyCa is dedicated to support, education, and communication for thyroid cancer survivors, their families, and friends, as well as raising awareness for early detection, outreach to health care professionals and the public, and thyroid cancer research fundraising and research grants. ThyCa's Tax ID number is 52-2169434.

### Board of Directors, December 2014

Victoria Ballesteros, Corresp. Secretary  
Bridget Corcoran, Recording Secretary  
Karen Ferguson  
Ruth Kallio-Mielke, Treasurer

Mary Catherine Petermann, Chair  
Louise Samuel  
Howard Solomon

Kathryn Wall, Assistant Chair  
Cherry Wunderlich  
Kurt Alexander, General Counsel

### Executive Director

Gary Bloom

### Message from the Board and Executive Director

Dear Friends,

2014 marked the 20<sup>th</sup> anniversary of the 1995 beginning of our services. Our free services and resources reached people in more than 120 countries. The number of people diagnosed with thyroid cancer increased to another new record high. Our services result from the dedication of the hundreds of people whose time and talents make ThyCa services possible.

Many who serve are coping with the challenges of their own or their loved one's thyroid cancer. Many have lost loved ones to this disease. We are grateful for everyone's help, and for the generous support of our donors.

This year, we continued adding additional educational material to our web site. We held hundreds of events — support groups, workshops, seminars, and the annual International Thyroid Cancer Survivors' Conference. We developed new publications. We expanded our online support groups and our activity on social media — Facebook and Twitter.

As we dream of cures for all thyroid cancer, and mourn the sad losses of those who have lost their lives to thyroid cancer, we are proud to award more thyroid cancer research grants through our collaboration with the American Thyroid Association. Thanks to everyone's generous financial support, we strengthened and extended our programs and services. The donations to ThyCa directly support our services, awareness, outreach, and research funds.

We are excited about the many initiatives that ThyCa has developed, and about our constructive alliances with international, national, regional, and local organizations. We will continue to strengthen our services for everyone whose life has been touched by thyroid cancer, to ensure that no one feels alone as they cope with this disease.

We invite you to read this Annual Report and its overview of our services and accomplishments during 2014. Please visit our web site often <[www.thyca.org](http://www.thyca.org)>. We update it many times a week, with thyroid cancer information plus the latest news about ThyCa services and upcoming events, as well as new services and resources.

We are committed to further strengthening our efforts to help us all, and to find cures for all thyroid cancer. We wish you all the best of health,

—ThyCa's Board of Directors and Executive Director

## Medical Advisory Council

Our Medical Advisory Council includes 47 distinguished thyroid cancer specialists and other health care professionals. We greatly appreciate their guidance and dedication. Our advisors plus many other physicians and other professionals contribute their expertise through input and review of the medical information in our publications and on our web site. They participate in our events. They help ThyCa in many other ways. Our thanks to these professionals for the care and treatment they provide, their support of patient well-being, and their efforts to find cures for all thyroid cancer.

## Service Overview: Survivorship Education, Support, Resources, Public Awareness

Our services and resources serve people being tested, treated, or monitored for any type of thyroid cancer, as well as their caregivers and friends, health care professionals, and the public. Our numerous free services are made possible by numerous volunteers, ThyCa's employees, and in-kind and financial donations. Funding comes from membership dues, individual donations, and unrestricted operating grants. Among 2014 accomplishments:

**Web Site, [www.thyca.org](http://www.thyca.org).** Our redesigned web site has more than 800 pages. Materials are in 7 languages (English, Chinese, French, Italian, Japanese, Russian and Spanish). More than 50 leading thyroid cancer specialist physicians provide ongoing input and review of the medical content and publications.

**Major Web Site Sections,** developed by patients, caregivers, and physicians, cover Papillary/Follicular Thyroid Cancer and their variants, Anaplastic Thyroid Cancer, Medullary Thyroid Cancer, Pediatric Thyroid Cancer, Support Groups, Events, Awareness, Research Fundraising and Grants, Ways To Help, and more.

**Free Handbooks.** Our free handbooks are team projects combining the efforts of patients, caregivers, and numerous thyroid cancer specialist physicians and researchers. The handbooks are free for download in PDF format as well as in ePub format, and by mail, to individuals and in bulk to physicians to give to their patients. We distributed many thousands of copies during 2014.

- **Thyroid Cancer Basics** is 50 pages long, covers all types of thyroid cancer. It's available in English, Spanish, and Chinese.
- **Anaplastic Thyroid Cancer Handbook** gives key information about the rarest and most aggressive thyroid cancer.
- **Medullary Thyroid Cancer Handbook Preview** explains both sporadic and hereditary medullary thyroid cancer, another rare thyroid cancer.

**Free Low-Iodine Cookbook:** The 7<sup>th</sup> Edition of our acclaimed free Low Iodine Cookbook, is available in English, French, and Spanish. Downloadable 1-page Low Iodine Diet Guidelines are in English, Japanese, and Spanish. Please share these with your medical team. Medical advisors and research dietitians provided input.

**Patient Information Packets.** We mailed thousands of free individual Patient Information Packets worldwide, plus packets in bulk to physicians. Packets are available on request.

**ThyCa Newsletter.** Our free weekly online newsletter went each month to more than 50,000 people in over 100 countries. It is also on our web site.

**Online Support Groups.** ThyCa's online groups grew to more than 30,000 participants at the end of the year. Our 12 e-mail groups and Inspire online community support people around the world 24 hours a day. Our group support began with an online chatroom in 1995. This was the world's first thyroid cancer support group.

**Local In-Person Support Groups.** Our local support groups began in 1996 and have grown to more than 100 groups in 5 countries: United States, Australia, Canada, Costa Rica, and Philippines. They provide important face-to-face support and local networking to thyroid cancer survivors and caregivers.

**One-to-One Support.** Our Toll-Free Number Team (English & Spanish), E-Mail Response Team (English & Spanish), Person-To-Person Network (matches patients with volunteers with the same thyroid cancer type), and additional support volunteers gave 1-to-1 service to over 7,500 individuals and organizations this year.

**Chinese, French, Italian, Japanese, Russian, and Spanish Translations.** Downloadable materials include thyroid cancer fact sheets, the handbook *Thyroid Cancer Basic*, low-iodine diet guidelines, and low-iodine recipes. In addition, an endocrinologist from China, trained at Johns Hopkins, translated our web site's thyroid cancer content into Chinese. More translations are in development.

**Videos.** Our web site has numerous videos and webinars with physicians, patients, and a caregiver, plus thyroid cancer public service announcements.

**Free Guestbook/Subscriptions.** Through our Guestbook, web site visitors can subscribe to our free online newsletter and e-mail announcements.

**Outreach.** We provided more than 140,000 free brochures and other materials to physicians, hospitals, individuals, and community groups.

**Workshops and Seminars.** ThyCa sponsored free one-day Regional Workshop in California, Maryland, and Missouri. Support groups sponsored dozens of seminars with physician speakers.

**Annual International Conference.** Our 17th Annual International Thyroid Cancer Survivors' Conference in Denver, Colorado, had over 60 speakers and 600 people from around the United States, Canada, and the United Kingdom. The 18th International Conference will be held in St. Louis, Missouri, on October 2-4, 2015.

**Thyroid Cancer Awareness Month.** ThyCa sponsors Worldwide Thyroid Cancer Awareness Month each September. Individuals and organizations again partnered and collaborated in this important observance. Year-round campaigns by ThyCa volunteers, medical professionals, and community organizations further raise awareness of thyroid cancer, neck checks for early detection, treatment, and lifelong monitoring. Our web site has details plus free tools and tips.

**Thyroid Cancer Awareness Brochures Feature Actress Catherine Bell, Thyroid Cancer Survivor.** We have distributed over 560,000 copies worldwide.

**Pediatric Backpacks.** Initiated by a teenage thyroid cancer survivor, Pediatric Backpacks are filled with booklets and ThyCa Awareness items. We have given backpacks to young people and families throughout the U.S., Canada, Philippines, and United Kingdom.

**Thyroid Cancer Spirit Items Support Outreach and Awareness.** Again in 2014 we distributed thousands of Thyroid Cancer Awareness Wristbands, Magnets, Ribbon Pins, Bracelets, and other Spirit Items worldwide. Proceeds support our support services and thyroid cancer research.

**Meetings and Exhibits.** ThyCa took part in more than 50 professional meetings, seminars, and health fairs in 2014; including the American Academy of Otolaryngology, American Association of Endocrine Surgeons, American Society of Clinical Oncology, American Thyroid Association (ATA), the National Comprehensive Cancer Network, and the Society for Nuclear Medicine and Molecular Imaging.

**Patient Experiences Surveys.** We posted patient surveys on [www.thyca.org](http://www.thyca.org) in 2014, in collaboration with medical advisors. Results will be reported to medical professionals and ThyCa. ThyCa has cooperated with medical experts in numerous surveys since our first international survey in 2004.

**FNA Procedure Manual for Physicians.** ThyCa distributed numerous copies of this resource by Yolanda Oertel, M.D., a ThyCa's medical advisor.

**Facebook (THYCA).** Our Facebook page grew to over 12,000 friends and provides ongoing news and updates.

**Twitter (ThyCaInc).** Our Twitter page, launched in spring 2010, grew to 2,200 followers by the end of 2014.

**Cabozantinib and Vandetanib Approval by FDA.** ThyCa and our online MTC community have actively participated in education and advocacy regarding new drug development and FDA approval. We're very pleased that the U.S. Food and Drug Administration has approved vandetanib and cabozantinib for progressing metastatic medullary thyroid cancer (MTC).

**AACE Neck Check Card.** Thanks to our collaborative relationship with the American Association of Clinical Endocrinologists (AACE), ThyCa distributed many thousands of AACE Neck Check Cards free of charge worldwide.

**HPTH Collaboration.** ThyCa and the Hypoparathyroidism Association (HPTH) continued our collaboration in support of our shared goal of reducing post-surgical hypoparathyroidism, which results in lifelong calcium issues and their many associated challenges.

**New Grants to Thyroid Cancer Researchers.** We continued our research grants program and proudly awarded 6 grants: 3 new thyroid cancer research grants, as well as 3 continuation grants (year 2). This is our 11<sup>th</sup> consecutive year of awarding thyroid cancer research grants, for a total of 47 grants. Grants are open to researchers and institutions worldwide.

**NORD Support.** ThyCa participated in publicizing Rare Diseases Day, an important awareness observance of the National Organization for Rare Disorders (NORD).

**Financial Supporters and Grantors.** ThyCa's free services, publications, events, and outreach are made possible by our volunteers and generous financial support of our members and individual donors, as well as through unrestricted educational support from our year-round financial supporters. Our thanks to our 2014 Grantors: Akrimax, AstraZeneca, Bayer/Onyx, Eisai, Genzyme, NPS, OXiGENE, and Veracyte.

**Volunteers—Thank You.** Thanks to our more than 400 volunteers for the tremendous efforts you contributed.

## Research Fundraising and Grants

ThyCa: Thyroid Cancer Survivors' Association, Inc. began fundraising for thyroid cancer research in 2001 to expand of urgently needed thyroid cancer research,

In 2003, we proudly awarded the first-ever patient-funded Thyroid Cancer Research Grant. We have continued to award research grants each year.

We have awarded 47 grants to researchers in 6 countries and totaling more than \$1.3 million.

**ThyCa sponsors two Research Funds. We welcome contributions of any size.** Our Thyroid Cancer Research Fund is dedicated to research on papillary, follicular, variants, and anaplastic thyroid cancer. Our Medullary Thyroid Cancer Research Fund is dedicated to research on medullary thyroid cancer.

**Thanks to continuing growth in donations, ThyCa awarded six scientific and clinical research grants in 2014,** in collaboration with the American Thyroid Association. ATA experts reviewed applications and selected the recipients.

We plan to award 6 more grants in 2015. One grant is the Ric Blake Memorial Thyroid Cancer Research Grant in memory and honor of ThyCa Co-Founder Ric Blake. Our web site has details about our grants and recipients.

**Thyroid cancer survivors, loved ones, and medical professionals have all joined together in varied ways to raise funds and awareness.**

**What we are doing ensures that no one with thyroid cancer diagnosed in the future will have to feel as alone as we did.**

Keys to fundraising success were the ongoing donations in honor of loved ones and in memory of loved ones and to commemorate special family occasions. We are most grateful to everyone who donates to ThyCa. ThyCa was again accepted into the Federal Government's Combined Federal Campaign (CFC), the world's largest workplace giving campaign.

We also thank the many volunteers who initiated highly successful individual fundraisers during the year. The Megan Stendebach Memorial Golf Tournament hosted by John Oaks, the Strokes for Hope Golf Tournament hosted by Scott Jordan, 4th Stage Cycling organized by Rob Bohning, and Andrew's Triathlon for All People with Cancer Like Daddy's were among the creative fundraisers. Another event, our 13<sup>th</sup> Annual Benefit Dinner/Auction, was an inspiring evening of tribute and support, held in conjunction with our annual conference.

Additional Rally for Research events have included birthday celebrations as fundraisers, Marathon Runs, Concerts, and Individual Walks dedicated to ThyCa's research funds. The consistent theme is that each donation makes a difference.

**Through these wonderful efforts, we hope that the future will bring cures for all thyroid cancer.**

## Statement of Financial Position

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

For the Years Ending December 31, 2014 and 2013

ASSETS	2014	2013
Cash and Cash Equivalents	\$761,746	\$822,008
Inventory	\$10,093	\$11,270
Receivables	14	50
Other Assets	\$2,475	\$2,215
Equipment, Net	\$1,334	\$2,872
Total Assets	\$775,662	\$838,415
LIABILITIES AND NET ASSETS		
Liabilities	\$32,334	\$14,697
Net Assets and Liabilities	\$743,328	\$823,718
Designated Assets	\$241,180	\$188,901
Revenues	\$539,373	\$463,868
Expenses (See Note 1)	\$619,763	\$552,789

#### Notes:

- 2014 and 2013 expenses include thyroid cancer research grant distributions of \$172,500 and \$172,500.00, respectively. They also reflect the added start-up and continuing expenses for several initiatives, including the handbook series and translations, the conference session video/audio recordings, further web site enhancements, and other new initiatives.
- ThyCa's audited financial statements are available upon written request. ThyCa's 2014 audit has been completed.

## Thank You

Our special thanks to all our constituents, our volunteers, our medical advisors, and our donors for your terrific support and involvement in 2014. Truly, you're all helping make a difference to people whose lives have been touched by thyroid cancer. We look forward to an even better year of service and support in 2015.