



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.

Spring 2003

My Story

by Tina Anders

Facilitator, ThyCa Denver, Colorado, Support Group

(Editor's Note: This month, ThyCa Journeys profiles thyroid cancer survivor Tina Anders of Boulder, Colorado. Tina, along with her children Garet and April, was diagnosed with medullary thyroid cancer in 1999. Medullary thyroid cancer, which sometimes runs in families, occurs when the thyroid produces excessive amounts of calcitonin. Metastases can occur throughout the lymphatic system to bones, the liver, and lungs. Treatment of medullary thyroid cancer involves a total thyroidectomy.

Tina has written her story to share her experiences with her family, friends, fellow survivors, and now, with Journeys' readers. She believes that being a part of ThyCa has helped her cope with her disease.

"I feel less alone in this disease. I got so much support from others in 2001 and 2002 to help me survive the worst time in my life; now that I am helping others it feels great. Running a support group in Colorado has brought new friends into my life that I never would have met before." Most importantly, she credits her husband, Tony, as being her "rock to hold onto through all of this." As Tina notes, "Many cancer people call their new life a journey once the diagnosis hits. While we don't choose this journey, we can choose the paths that lead us through our lives."

For many years our family did not have insurance. I was a part-time Mom at home, and went to school for an Associates in Accounting. In April 1999, my father helped us buy the Automotive Repair Shop, Integrity Motors, where my husband worked. Part of the deal was that we would finally get health insurance.

I picked a doctor for me to see for the fun yearly physical. While there, we discussed some symptoms that I had been having. I also showed him bumps on my eyelids that were concerning me. He then sent me to an ophthalmologist to get a diagnosis of what these were. This doctor sent me to another doctor, who then sent me to an eye plastic surgeon to get a bump removed and biopsied.

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Letter from the Editor

Dear Readers,

Welcome to the Spring 2003 edition of Journeys! As the cold days give way to warmer weather, I'm reminded that for several years, I had a Pavlovian revulsion to the arrival of summer. That season brought with it my inevitable annual papillary thyroid cancer follow-up scan—and its accompanying anxiety.

And then, things began to change. First, a few years ago, my doctor and I decided that it would be ok for me to wait a little longer between scans, allowing me to enjoy a stress-free summer for the first time in several years. Then, slowly, my test results began to improve. And this past February, I had my first fully clean thyroid scan.

The clean scan took me by surprise. After four years of frustrating test results, I had become accustomed to a certain behavioral pattern: I would spend a few months not focusing too much on my health, and as the end of the third month drew near, remember a blood test was on the horizon. Anxiety would set in. Suddenly, the unexpected clean scan has freed me from my pattern.

Although my tests and scans will now be spaced further apart, I'm sure they will elicit the same level of anxiety when they occur. How could they not? As any thyroid cancer survivor knows, this is a disease that can easily recur and vigilance will always be essential. But now, I've begun a new phase in my life as a survivor. I no longer dread the coming of summer and this year, I'm looking forward to it more than ever.

I hope you enjoy this edition of Journeys, and welcome you to share your story in future editions. Feel free to e-mail me at newsletter@thyca.org.

—Barbara Weinstein, Editor

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My Story—cont.

At every step along the way, I told all the doctors about my eyes and my “spells,” as I called them. My “spells” always came when I was lying down - I would get short of breath, shaky, sweaty, headaches, and it would only last a few minutes. If I changed positions, or got up, they would go away. These were the symptoms of the pheochromocytoma I had. (Pheochromocytoma is characterized by a tumor that arises from tissue in the adrenal gland and results in increased production of adrenaline and noradrenaline, which raises blood pressure and heart rate.)

The last doctor became my hero because he put all the pieces together and determined that my children and I had Multiple Endocrine Neoplasia Type 2b. We knew the kids had it because over the summer we had their eyes examined.

So they tested the kids’ blood, and got the results right before Christmas. Merry Christmas, you have cancer, and if your kids don’t have it now, they will eventually. So right before Christmas, I had another MRI of the abdomen, and thyroid ultrasound, and a chest x-ray. This confirmed medullary thyroid cancer (MTC), but no metastases showed up on these scans.

So, on January 3rd, they removed my right adrenal gland in laparoscopic surgery. During that surgery, the doctors looked at my liver and took out a little to do pathology tests on. Sure enough, I had liver metastases. At that point, we decided to go ahead with my total thyroidectomy and neck dissection because I/we just wanted as much of the cancer out of me as possible.

My life was altered after the MTC operation. Before this operation, my stepmother told me, “It’s no big deal to have your thyroid removed. You’ll just take a pill for the rest of your life.” (Wrong, I now take about twelve a day). When I came out of surgery 9 1/2 hours later, they had done the full operation -- neck dissection on both sides. I had four drainage tubes, and a tracheotomy, so couldn’t talk. The trach was because my neck was swelling and they wanted to make sure I could breathe. My post-op CT only showed metastases to the liver, which we already knew about, because of my previous surgery.

Shortly after moving to ICU, my whole face suddenly began feeling numb and tingly. Over time, that sensation went over my whole body and it scared me. My muscles began to tense up, and I remember I couldn’t move one of my thumbs. This went on for hours! First they had to figure out why, and then do a blood test to check my calcium level, then order the calcium IV drip, wait for it to arrive, and then wait while it SLOWLY went into my system. It was terrifying. My doctors and I have all concluded I am suffering from post-traumatic stress disorder due to this. I was also throwing up from the anesthesia, and reacting to the pain medications, getting rashes, itching, and HOT!

I could never be alone from then on during my stay at the hospital. My husband or my sister HAD to be there 24/7. During their coffee breaks I was miserable! For a while I could sleep only if they were holding my hand. I was not given much pain medication until I could finally swallow a few days later. The tubes hurt!!!!!! Especially when they were removed!

When they released me, I was so happy. The first few hours at home I just lay on my bed and enjoyed the quiet. But then the fear came creeping in on me. We spent one evening at the Boulder Hospital because I was sure my calcium was too low. It was a little low, so they gave me an IV drip then sent me home.

I couldn’t eat, so I was living off protein drinks, OJ, and my meds -- and crying all the time. Sleep was rare, and very restless! Two days later I was back at the Denver hospital having more panic attacks about my calcium. My surgeon admitted me for two days, during which time I saw a psychologist, and got some rest.

The next day I went back to my regular doctor. He has since become my newest hero, and an all-great doctor to me. I used to see him every week to get my calcium drawn, and he’s monitoring the kids now, too. My doctor really is my life-line, and I feel so comfortable with him. He hugs my kids, he hugs me, and he really treats us like PEOPLE, not numbers. Although I’m not very religious I believe he was a gift from God to me in all this.

So, I came home and was having a VERY slow recovery. My first TSH came back, and it showed I was getting too much thyroid replacement hormone. Adjusting this and my other medication and calcium was difficult.

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Come to Houston!

The 6th International



Thyroid Cancer Survivors’ Conference

October 24-26, 2003

Wyndham Greenspoint Hotel

Houston, Texas

Details and registration—www.thyca.org

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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.

My Story — cont.

The calcitonin (measured as part of testing in people with medullary thyroid cancer) is also a problem. Prior to surgery it was 62,000. Then it was 41,000. Now it's at 26,000.

My voice is also quieter since one of my vocal cords was paralyzed during surgery. Most of the time that doesn't bother me, until we go out in public, and no one can hear me, and my kids run off, and I have no way to call them back. I've now attached a whistle to my key chain, so they know when to come running...It took a long time, but my voice is much better, but I still have times where it's gravelly, and raspy. Once again, though, I have to be so thankful that I even have a voice! The thyroplasty I had recently to help my voice improved the situation: my cough is better now, but my voice is quiet and still healing.

My son Gareth is now 11 and my daughter April Rose is 10. Their surgeries were originally set soon after mine, but they had to wait a couple of weeks so I could get better. My kids were lucky, especially my son. Because of what I went through, I had them put into ICU after surgery, and their calcium levels were watched very closely. Gareth's began to drop, but he was given calcium right away!!! Two of his parathyroids were in his thyroid, and they were removed during surgery by accident. Had I not insisted on his calcium being watched, he might have gone through what I went through.

My daughter's surgery cured her of the cancer!!!! Unfortunately Gareth isn't so lucky. It's still in him somewhere. He had a CT scan in Denver, another one in Boulder, and a neck ultrasound. He had a second surgery in April 2001, involving a neck dissection. It was a tough recovery. For some reason his scar doesn't heal like mine does. His post-op calcitonin is still elevated so he still has some cancer in him somewhere.

A big problem I had was weight loss. I was 124 pounds in January of 2000, and went all the way down to 92 lbs by August! And I would eat. The weight loss finally stopped after I received a different antidepressant medication. The next day it felt like a light switch had been turned on...I ate for weeks!!! I am now up to 130 pounds, and eating normally. YEA!

It's a rough road. A friend with MTC suggested I got a book called "Simple Abundance, A Day Book of Comfort and Joy." It's a spiritual book to help women get to know themselves, and love, joy, abundance, happiness, Grace, etc... This book has helped me a lot!!!

Getting a doctor and surgeon with experience with medullary thyroid cancer is VERY important so that the patient gets the best care possible. Many doctors who might be great in some areas do not know enough about medullary thyroid cancer because it is rare. Medullary patients really need to be their own advocates and get the best care possible.

Thyroid cancer has had a HUGE IMPACT on my life!! It has changed how I take on every day. I learned not to sweat the small stuff. Enjoy the day. When I was depressed, I also learned that getting better doesn't happen overnight. When someone is in deep depression for whatever reason, they must give themselves small, attainable goals for each day and take baby steps toward getting better.

ThyCa's Thyroid Cancer Survivors' Conference is an amazing thing to be a part of. Having thyroid cancer wreaks havoc on one's emotions. Going to the conference and hearing all these people saying they are going through so much of the same things really helps one's mental state.

Also, seeing all the doctors, and hearing from them, and realizing that there REALLY are great doctors out there who care about us, and want to help ALL thyroid cancer patients...that gives me strength and reassures me that the world has good people in it. I am proud to be part of ThyCa!

ThyCa Hosts Spring Workshops

ThyCa volunteers in four parts of the country are organizing free one-day and half-day workshops this spring. If there's one near you, plan to attend as a great way to meet other thyroid cancer survivors and caregivers. For details, visit our web site in the Conferences/Workshops section.

On April 5, 2003, ThyCa sponsored the Thyroid Cancer **Capital Area Survivors' Workshop** in Fairfax, Virginia. The five physician speakers answered questions about diagnostic issues, nuclear medicine, and thyroid cancer management over the long term. In addition, there were survivors' and caregivers' roundtables led by ThyCa volunteers Sara Gorrell Brenner, Gary Bloom, Dunya Hecht, and Marty New.

The day was well attended and well received. Many thanks to the terrific speakers and all the volunteers who helped!

The other upcoming regional workshops:

New England Workshop

Saturday, May 3, 2003 • Nashua, New Hampshire

New York/New Jersey/Southern Connecticut Workshop

Sunday, June 8, 2003 • New York City, New York

Rocky Mountain Workshop

Date to be announced • Denver, Colorado

ThyCa News Nuggets

- **ThyCa's largest e-mail support group now boasts more than 1,100 members!** The seven e-mail groups are all listed in the Support Groups section of the ThyCa web site. If you're an America Online subscriber, remember also the live online Thyroid Cancer Mutual Support Groups for an hour each Monday and Tuesday evening.
- **The first-ever thyroid cancer research grant to be sponsored by ThyCa: Thyroid Cancer Survivors' Association, Inc. (ThyCa)** will be awarded in 2003, ThyCa Board Chair Gary Bloom has announced. The American Thyroid Association, the professional association of clinicians and researchers concerned with thyroid diseases, is selecting the recipient of the ThyCa grant.
- **ThyCa is proud to announce that we have established a Medullary Thyroid Cancer Research Fund.** The Fund will support research focused specifically on medullary thyroid cancer. This fund joins the **Thyroid Cancer Research Fund** already established to support research on papillary, follicular, Hurthle cell, other variants and anaplastic thyroid cancer. For more information, or to donate to the Fund, visit < www.thyca.org >.
- On Saturday, March 15, ten public health officials from Belarus took part in a **ThyCa Twin Cities** support group meeting in Edina, Minnesota. The officials were part of a month-long Community Connections program funded by the U.S. Department of State and sponsored by Connect/US-Russia of Minneapolis. The Belarusian attendees serve one of Europe's areas hardest hit by the 1986 Chernobyl disaster, which resulted in high levels of thyroid cancer, particularly among children.
- Our thanks and congratulations to **Sara Gorrell Brenner**. Sara helped fund thyroid cancer research by participating in a marathon run this past March. Friends and relatives helped sponsor Sara's run with donations to ThyCa's Research Funds. Sara is a ThyCa Board member and Facilitator of the Northern Virginia ThyCa Support Group.
- We are pleased to announce that ThyCa received a donation from the New Hampshire Partnership for End-of-Life Care, as part of a recognition award for ThyCa volunteers **Diane and Ric Blake**. They were recognized for their service and leadership in conducting a series of workshops at Holy Family Hospital in Methuen, Massachusetts last year.
- Many thanks to ThyCa volunteers **Evelyn Gross** of Pennsylvania, **Christine Lanotte** of New York, and **Jo and Ed Walker** of Arizona for organizing displays of ThyCa support service materials at recent cancer education and physician meetings in their areas.
- **Gary Bloom**, ThyCa's Board Chair and Facilitator of the ThyCa Washington, DC, Support Group, was named to CARRA (Consumer Advocates in Research and Related Activities), the consumer advisory organization of the National Cancer Institute of the National Institutes of Health in Bethesda, Maryland.
- **The thyroid cancer researchers at the National Institutes of Health (NIH)** continue to conduct studies of metastatic papillary and follicular thyroid cancer. The research program continues to accept patients. **Monica Skarulis, M.D.**, Endocrinologist at NIH, is a member of our Medical Advisory Council.
- **ThyCa has announced its support of the American Thyroid Association statement** on the need for the availability of Potassium Iodide in the event of nuclear emergencies. The statement, background information, and a list of reliable sources of potassium iodide are on the ATA web site <www.thyroid.org>. Our Journeys Newsletter's Spring 2002 issue has an interview with ThyCa Medical Advisor **Kenneth D. Burman, M.D.**, Endocrinologist, Washington Hospital Center, Washington, DC, on potassium iodide and the thyroid gland. The newsletter is on the ThyCa web site <www.thyca.org> in the Newsletters section. The article is on page 4.
- We are excited to report that **our web site receives more than 100,000 visits each month**, thanks to the great work of ThyCa's volunteer webmistress, **Betty Solbjor**! Among the new additions to the web site is the ThyCa Events Calendar, linked from the right side of the Home Page.
- **Also new on the web site is the Volunteer section**, where you can read about volunteer opportunities and e-mail our Volunteer Coordinator, **Peggy Melton**, at volunteer@thyca.org. Peggy is the facilitator of the ThyCa support group in Dallas, Texas.
- ThyCa's gone hi-tech! **You can now become a ThyCa member and register for conferences on-line!** Visit the web site's Membership section for the membership form and the Conferences/Workshops section for the conference registration.

A Letter from Emily

(Editor's Note: This letter was recently sent to ThyCa by Emily, the daughter of a thyroid cancer survivor, and is reprinted with her permission.)

Hello, my name is Emily. For my biology class, I was asked to research two types of cancer and I chose thyroid cancer because it really hit home with me. I wanted to know what causes it because when I was younger my mother was diagnosed with thyroid cancer. At the time I really couldn't understand what cancer was, but now that I am 17, I understand how serious the disease is.

I found that your web site was very informative....Having my mom in my life and free of cancer is the best feeling. I know not everyone might be as fortunate as my family was, but I can sympathize with them. I could just imagine what it's like getting the news that you have cancer. It must be really scary. I know that without my mom I would have had a very different life. I wouldn't have someone to talk to about all my problems. I love her so much and am very glad that she survived. I don't think her thyroid cancer was very bad because she caught it in the early stages and that made it easier to treat.

I wish that no one would ever have to go through any pain and could be cancer free. I think your web site is really well planned out and it's nice to see that people that have survived have others to talk to that have gone through the same thing. Well, I don't know if this e-mail will matter, but I thought I would e-mail you to tell you what a good job you are doing. Too bad there weren't more people out there that cared this much about thyroid survivors.

Sincerely,
Emily

Mark Your Calendar!

6th Thyroid Cancer Survivors' Conference Coming in October

Remember ThyCa's **Sixth International Thyroid Cancer Survivors' Conference October 24-26, 2003, at the Wyndham Greenspoint Hotel in Houston, Texas!** Confirmed speakers include leading physicians involved in thyroid cancer treatment and research, as well as mental health professionals and thyroid cancer survivors.

This educational and supportive event is a wonderful opportunity for people at all phases of testing, treatment, and follow-up for all types of thyroid cancer to share experiences, give and receive support, and learn about treatment, testing, and research advances from prominent thyroid cancer specialists. Details are on our web site <www.thyca.org>.

Graves' Disease Conference.

If you know someone with Graves' Disease, another disorder of the thyroid gland, let them know about the Graves' Disease Patient/Family conference also taking place October 24-26 in Houston, Texas, at the same hotel as the Thyroid Cancer Survivors' Conference. The sponsor is the nonprofit organization National Graves' Disease Foundation <www.ngdf.org>.

Our Rally for Research

Sara Gorrell Brenner's Marathon Run launched our spring Rally for Research, to support research on all types of thyroid cancer. The Rally continues all spring. We are proud to have been able to fund our first grant.

Please join our Rally for Research 2003 as we work toward our dream of a cure for all thyroid cancer. The details and donation forms are on our web site. Thank you for your support!

Have You Checked Out the ThyCa Web Site Lately?

The web site is chock full of information for newbies, long term survivors, caregivers and family members.

Our low-iodine cookbook is available free for downloading and provides recipes for even the most hypothyroid chef. The humor section provides enough jokes and goofy songs to bring a smile to anyone's face.

Information about testing, thyroid cancer variants, and clinical trials will assist any patient looking to improve his or her knowledge and impress the physicians. Log on now to see what you've been missing and check back regularly for important updates about conferences and more.

Help Us Help Each Other.

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



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

www.thyca.org • thyca@thyca.org • Toll Free 1-877-588-7904

Help Support Our Efforts for Thyroid Cancer Research... *Walk With Us!!!*

Dear Friends,

We invite you all to join in and be a part of our "Walk With Us" for Thyroid Cancer Research. May 18th is our designated ThyCa Rally for Research Day, but please join us whenever, wherever and with whomever you are able to do so.

Consider a walk in the park, a walk around the block, or even a walk around your house...but please consider "A Walk" of some kind.

Perhaps your family, support groups, friends, co-workers, or neighbors would like to sponsor you....please ask them.

We are all concerned about the urgent need to further the Research of Thyroid Cancer, and this is a wonderful way to support our efforts of funding Research Grants. By joining us, you will help us be one "STEP" closer to our hope of a cure for all Thyroid Cancer.

Please join with us all, as we put our feet together and stomp, shuffle, or "WALK, ONE STEP" at a time, in our fight against Thyroid Cancer. Together, we can and will make a difference!

Thank you so much for your support.

Gary Bloom
Board Chair

Joann Chaikin Eskenazi
Fundraising Chair

 Yes, I will Walk for Thyroid Cancer Research on _____(date)

Yes, I will sponsor _____(name) to Walk for Thyroid Cancer Research.

Here is my donation to the

Thyroid Cancer Research Fund (papillary, follicular, Hurtle cell, variants, anaplastic)

Medullary Thyroid Cancer Research Fund

Name _____

Mailing Address _____

City _____ State/Province _____ Zip/Postal Code _____

Phone _____ E-mail _____

Research Fund donation \$ _____

My check or my sponsor's check payable to ThyCa is enclosed.

Please charge my Visa Mastercard

Card# _____ Exp _____

Name as it appears on the Card _____

Signature _____

This gift is from me personally On Behalf of my Company/Organization

My employer will match my gift (form is enclosed)

Mail this form and your donation to ThyCa Walk, PO Box 1545, New York, NY 10159-1545

THANK YOU FOR JOINING US IN OUR EFFORT TO STRIKE OUT THYROID CANCER