no one should face cancer alone

1994 to 2014

Cancer Resource Center of the Finger Lakes
The Cancer Resource Center of the Finger Lakes has become a well-established organization in Tompkins County. While our services have evolved over the past twenty years, our mission remains rooted in the vision of the founders of the Ithaca Breast Cancer Alliance (IBCA). Here’s a look back...

A Pressing Need in the Community
During the decades leading up to the 1990’s, breast cancer was rarely discussed in public. Women who heard the words “You have breast cancer” were plunged into isolation. People were made so uncomfortable by the mention of cancer that most referred to it as The Big C. And breast cancer was an especially taboo subject because of its connection to sexuality and modesty.

During the 1980’s, women were commonly told by their doctors, and even more firmly by American culture, “Don’t mention your breast cancer. Have your procedures, get a good padded bra, and put it behind you. Return to your life as usual.” Ordinary women with breast cancer were invisible. But the number of women diagnosed with breast cancer began to mushroom, and many began to question that approach.

The AIDS movement paved the way for the breast cancer movement. Taboos were being broken down at record speed. Women with breast cancer began to speak out. They wanted information and explanations. They wanted second opinions. They wanted to talk with other women with similar life circumstances and the same type and stage of breast cancer. They wanted answers to what causes breast cancer. They became very visible.

Across the country, grass roots organizations began to develop with the mission of providing emotional support, better access to information, and practical help in navigating the challenges of managing treatment and daily life.

IBCA Founders, 1993
In 1992, Andi Gladstone, who would become a driving force and the first director of the Ithaca Breast Cancer Alliance, was diagnosed with breast cancer in New York City. There, she could do research at medical libraries and found personal support at SHARE, a NYC breast cancer and ovarian cancer support organization. In August 1993, a couple of months after Andi had moved back to Ithaca, Ned Asta was diagnosed. She went to her friend Andi, who said, “Let’s go to the breast cancer advocacy group.” There was no group. During Ned’s treatment, they often said, “What about the women who don’t happen to know someone? We should do something.” And do something they did.

They found six other women who had breast cancer or had been actively involved in helping someone close to them negotiate diagnosis and treatment, and they began meeting with the intent of creating a local organization to help those newly diagnosed with breast cancer. They worked quickly. Andi, Anne McLaughlin, and Meg Ambrey took key positions in getting IBCA organized. This was before cell phones, email, and the Internet—their answering machines got a workout.

They settled on a name and defined the mission:
The Ithaca Breast Cancer Alliance (IBCA) is a group dedicated to providing support, education, and advocacy for all Tompkins County women facing the breast cancer epidemic. Among our membership are women who have individually chosen many different paths of treatment, and we are united in our fundamental belief that each woman must decide for herself which treatment is best. We do not advocate one treatment over another, rather we support each woman in her individual choices.

They established IBCA’s goals:
• Publish a quarterly newsletter to keep us informed on breast cancer issues and treatments
• Develop an information network that will enable newly diagnosed women to talk with breast cancer survivors about their experience
• Identify and train a pool of volunteers (buddies) to help breast cancer patients get to and through their doctor’s appointments and treatments
• Establish and coordinate support groups
• Develop a resource center and library
• Set up a speaker’s bureau to raise awareness and do outreach

how it began...

1993
• A group of nine women (Joan Adler, Meg Ambry, Ned Asta, Andi Gladstone, Jackie Livingston, Nancy Lazarus, Anne McLaughlin, Bo Stapha, and Annie Wilson) began planning what would become the Ithaca Breast Cancer Alliance (IBCA).
• Shindig 1 was held at Common Ground in December, raising $800.

1994
• IBCA became an organized, non-profit corporation.
• First support group.
• Resource Center opened at 706 W. Green Street.
• First Walkathon raised $4,035.
By spring 1994, they were gathering materials for the Resource Center, organizing and training volunteers to begin the network and buddy services, and had printed the first issue of the newsletter, *Choices*.

During the last twenty years, much has changed: societal attitudes about cancer, medical advances, evolving doctor-patient relationships, the proliferation of support groups and other services, and the availability of information on the Internet. But what hasn’t changed is that when a person is told “You have cancer”, they and their loved ones need information, support, and community.

**At CRCFL, we still begin by asking, “How can we help?”**

**IBCA Moves into a Permanent Space and Expands its Mission**

Almost immediately after IBCA was up and running, women came for help from nearby counties. People with cancers other than breast cancer called. Although IBCA programming was targeted to women with breast cancer, assistance was provided on a one-to-one basis to whoever walked through our doors.

A decade after the founding of IBCA, the breast cancer movement’s awareness and advocacy campaigns had effectively removed the stigma that had isolated women with breast cancer. Educational, emotional, and practical assistance for women with breast cancer was available all across the country. Medical information was readily accessible in the popular press and on the Internet, and it was accepted in the medical establishment that patients should be active participants in treatment decisions. What had once been revolutionary had become simply something that could be taken for granted.

A multi-year discussion began in the early 2000’s as to whether IBCA should expand to other cancers, or maintain its focus on breast cancer. On one hand, IBCA was clearly rooted in the Women’s Movement and there was a recognized need to provide a safe place for women with breast cancer. On the other hand, individuals in the community with other cancers weren’t being served.

In 2005, IBCA’s mission was expanded to include women with gynecologic cancers since those cancers fit closely with IBCA’s original mission and because breast and ovarian cancers were closely linked biologically.

At about the same time, a search began for permanent office space and a house was eventually purchased on West State Street. Renovations were completed with considerable support from local labor unions and contractors.

In 2007, the decision was made to expand the mission to serve women and men with all types of cancers. In addition to serving many more people, it was thought that an expansion would better serve women with breast cancer by improving our capacity to offer a wider range of programs and our capacity to raise funds from a variety of sources. The name was changed to the Cancer Resource Center of the Finger Lakes to reflect our service to a broader community.

continued on page 6
Program Highlights....

Most people know that we offer a variety of support groups (see page 7) and one-to-one assistance, but we’ve developed a variety of creative programs to serve our community. Here are just a few:

Collaboration with Cornell Researchers

An innovative program connects the clients of the Cancer Resource Center with doctoral students and post-doctoral fellows engaged in cancer research at Cornell University.

Each month, a seminar is led by a student about a current topic in cancer research. The presentation is in lay language, and the discussions between researchers and our clients are quite lively. A few students also become regular participants in some of our support groups. One student wrote that “with this experience, the disease has evolved from a biological problem on a lab bench to something much more personal.”

As far as we know, this is the only program of its kind in the United States.

Organizing Notebooks

Most people in treatment for cancer have multiple doctors, countless appointments, and stacks of papers. We’ve created notebooks to help individuals stay organized. They have multiple pockets for loose papers, a sheet for business cards, and other useful accessories. These notebooks are a hit with our clients.

First edition of IBCA E-News goes out to 50 readers.

Workshop on counseling persons with cancer held for area mental health professionals.

2004

- IBCA video, Because no one should face breast cancer alone, created by volunteers Baseema and Ward Krkoska, wins National Public Access Award.
- New workshop offered to the community: I need to take a month off: Cancer and Your Job
- Hester Hill Schnipper, Chief of Social Work Oncology at Boston’s Beth Israel Deaconess Medical Center, presents Facing the Tiger Together: Working with Women with Advanced Cancer.

2005

- IBCA’s first corporate campaign, chaired by Steve Garner, President and CEO of Tompkins Trust Company, raises more than $60,000.
- A six-session education series is offered in collaboration with Hospicare & Palliative Care Services.
- A grant from the NYS Department of Health begins a pilot program by which assistance is provided to Cayuga Medical Center patients at the hospital.
- Mission expands to include gynecologic cancers and surrounding counties.
- IBCA purchases 612 West State Street to serve as permanent home.
One-to-One Assistance

Providing personalized assistance is our most important service. Nearly every day, someone comes through our front door and says, “I was just diagnosed with cancer and I don’t even know what questions to ask.”

What we do is begin by listening. We then answer questions, suggest resources, and share what we’ve learned from others who have come through our door.

Cornell Campus-to-Campus Bus

Many individuals from our area go to New York City for second opinions and specialized services. Thanks to the generosity of Cornell University, we are able to place cancer patients and a support companion on Cornell’s Campus-to-Campus bus for free when seats are available.

Boutique

A common occurrence during cancer treatment is hair loss. Our Boutique provides wigs, hats, scarves and other items—all free of charge.

2006

- Shawn Galbreath appointed Executive Director.

2007

- IBCA’s new home is renovated with considerable assistance from local labor unions and support from local businesses.
- Friday noon group for women begins.
- Name changed to the Cancer Resource Center of the Finger Lakes to reflect our service to everyone affected by cancer.

2008

- Ithaca Garden Club installs Victorian Garden in front of the office.
- First Women’s Retreat.

2013 Financials...

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Programs</td>
<td>81%</td>
</tr>
<tr>
<td>Fundraising</td>
<td>11%</td>
</tr>
<tr>
<td>Management &amp; General</td>
<td>8%</td>
</tr>
<tr>
<td>Donations</td>
<td>30%</td>
</tr>
<tr>
<td>Events</td>
<td>45%</td>
</tr>
<tr>
<td>Donated Materials &amp; Services</td>
<td>3%</td>
</tr>
<tr>
<td>Grants</td>
<td>22%</td>
</tr>
</tbody>
</table>

Revenues, Fiscal Year 2013

Total Revenues: $415,397

Expenses, Fiscal Year 2013

Total Expenses: $346,838

We thank our supporters for their generosity. The financial surplus at the end of 2013 allows us to make crucial reinvestments in the services that are so important and ensures that we can continue to provide services at a high level through the inevitable bumps in the road ahead.
Evolution of the Organization

One of the concerns about expanding our mission was the expectation that we would need to develop expertise on many different types of cancer. We quickly learned that we already had the expertise that most people want: how to communicate about cancer, how to find and evaluate information, and how to connect with people affected by cancer. The commonalities between types of cancer were more apparent than the differences.

Of course, by opening our doors to people with all cancers, we began serving men in much greater numbers. When assisting individuals on a one-to-one basis, we found that men and women weren’t too different in terms of their needs and the questions that they asked. But we quickly learned that men were less interested in attending support groups. They were willing, however, to get together for breakfast. Thus, we formed the Friday Men’s Breakfast Club that has become a vibrant support community.

One notable change that occurred with our expansion to all cancers was a heightened awareness of the needs of people with advanced cancers. With the development of more effective treatments, increasingly we’ve seen people who live with cancer as a chronic disease and we formed a support group for this population. We call it Pat’s class and other wellness programs with this group in mind.

We serve a significant number of people for whom cancer is only one concern of many. Financial problems are at the top of the list, and others deal with mental health issues, a lack of a safe living environment, stressful family situations, and other co-existing challenges.

We created a Boutique with wigs, hats and other items that are provided free of charge. We’ve found that many clients won’t come for emotional support per se, but they will come in for a wig or other practical assistance. While they’re here, they learn of our other programs. We want to provide multiple points of entry.

In 2006, we began serving cancer patients at Cayuga Medical Center. Most individuals with cancer in Tompkins County have some connection to CMC; our services more convenient for them by our presence at the hospital. This program began modestly, but has now expanded so that our volunteers (who are cross-trained as CMC volunteers) are available in chemotherapy and radiation therapy on a daily basis. This is a unique relationship between a locally-based cancer support organization and a community hospital.

From the very beginning, we have offered our services free of charge. During the past 20 years, our mix of funding sources has changed, but we continue to be dependent on donations, grants, and fundraising events. Our Walkathon, now coupled with a 5K run, remains our most important fundraising and outreach event.

CRCFL, A Community of Support for People Living with and Affected by Cancer

We hold tight to our mission, which is all about people—communication, support, connection. While the mission remains constant, the organization continues to evolve because our community is evolving.

2009
- First yoga class.
- First water therapy class.
- Cancer Resource Center named “Nonprofit of the Year” by the Tompkins County Chamber of Commerce.

2010
- Bob Riter appointed Executive Director.
- First Lynda Myers Interior Design event held to benefit CRCFL.
- 5K Run added to the Walkathon.
- Men’s Breakfast Club begins.

2011
- First Young Adult Support Group.
- Our collaboration with Cayuga Medical Center expands so that our volunteers are at the hospital on a daily basis.

2012
- First Annual Adventure Day for Men.
- First group of volunteer financial advocates trained with the assistance of a grant from the Park Foundation.

2013
- Work on the Healing Garden begins, under the direction of Volunteer Lee Ginenthal.
- Colorectal group begins.
- CRCFL wins a “To-Go” Award (Town-Gown) from Cornell.
Join Us...

All groups are offered free of charge and take place at the Cancer Resource Center, 612 West State Street, unless otherwise noted. For information about any group, contact us at info@crclf.net or 277-0960.

On-Going Programs

**Gentle Yoga Class**
A blend of stretching, relaxation, healing visualization, and meditation in a supportive group environment. **Meets every Tuesday from 9:30-11:00 am at Island Health & Fitness.** Offered free of charge to those with or recovering from cancer. You do not need to be a member of Island Health & Fitness to participate.

**Cancer Research Group**
Join with Cornell doctoral students engaged in cancer research and those directly touched by cancer for a discussion about the science of cancer (presented in lay language). The public is welcome. **Meets the 2nd Wednesday from 5:15 - 6:45 in the Hagan Room at the Cornell College of Veterinary Medicine.**

Support Groups

**Men’s Breakfast Club**
Men with any type of cancer and at any stage of treatment or recovery are welcome. **Meets every Friday from 8:00-9:00 am at the Royal Court Restaurant.**

**Women’s Noon Group**
For women with any type of cancer, at any stage of treatment or recovery. **Meets every Friday from noon-1:30 pm.**

**Young Adult Group**
For people 20-40ish with cancer; partners welcome. **Meets the 4th Tuesday from 5:30-7:00 pm.**

**New to Cancer Group**
For people newly diagnosed and/or their loved ones. **Meets every Wednesday from 10:30-11:30 am at Cayuga Medical Center—Medical Office Building, first floor.**

**Pat’s Group: Living with Cancer as a Chronic Disease**
For people with more advanced cancers; caregivers welcome. **Meets the 1st & 3rd Thursdays from noon-1:30 pm.**

**Colorectal Group**
Meets the 1st and 3rd Tuesday from 5:30-7:00 pm. For more information, contact Kerry Quinn at 277-0960.
Board

seated, left to right: Gary Stewart, Lynda Myers, Eileen McCoy Whang (Vice-President), Edward Moscato (President), Brian Wilbur (Secretary), Steven Novakovic (Treasurer), Julie Campbell, MD

standing: Paul Bates, MD, Lisa LiVigne, Linda Falkson, Anna Addario, Skip Hewitt, Hal Craft, Alison R. Smith, Sunny Donenfeld, Bob Riter (Executive Director)

Not pictured: Jo Ellen Hedlund, Molly Salley

Staff

Sharon Kaplan, Director of Volunteer Services

Jyl Dowd, Development Coordinator

Bob Riter, Executive Director

Kerry Quinn, Director of Client Services