Two of the many survivors impacted by studies conducted in our region by the recipients of our 2020 research grants, Kathy Simpson (left) was diagnosed with triple negative breast cancer in 2013, while Nancy Gramkee-Cuer (right) has been living with metastatic breast cancer since 2017.

For more information on our Research Initiative, see page 14.
OUR EXECUTIVE DIRECTOR

Holly Anderson

We Stand in Solidarity

It’s hard to watch what is happening in our city and around the country and stand by silently as we try to find the right words to say in response to what we are witnessing. And we can’t stand aside and say nothing hoping someone else will say it better. Racism is present in our community. Racism is a public health crisis and represents a longstanding paradigm of systemic racism that cannot be ignored. We grieve for the family of George Floyd. We grieve for the families of Breonna Taylor, Ahmaud Arbery, Freddie Gray, Laquan McDonald, Philando Castile, O’Shae Terry, Michael Brown, Trayvon Martin, Tamir Rice, Tony McDade, and the countless other Black people, named and unnamed, whose lives have been taken by the hands of those who have sworn to serve and protect. Our grief has turned to resolve; we must recognize ways we have been complicit and commit to becoming increasingly vigilant in seeking ways to eliminate racism, particularly in healthcare.

Just as cancer does not discriminate, the Breast Cancer Coalition recognizes the importance of a culture that strives for diversity. We honor individual differences whether color, race, religion, political viewpoints, socioeconomic status, physical abilities, gender, gender identity, and/or gender expression. We want everyone who comes to the Coalition for services to feel safe and accepted.

But everyone is not safe in our community. Everyone is not accepted. And we can no longer stay silent. Black lives DO matter. Racism has long been a factor in the disparities we see in cancer diagnosis and treatment. We have long known that the mortality rate for the Black, Brown, Indigenous, People of Color, and LGBTQ+ communities is measurably higher than for White women. We have long known that racism destabilizes public health and disproportionately impacts those with cancer. These populations are more likely to be diagnosed at a later stage and less likely to be offered clinical trials. They are least likely to be referred for genetic counseling, least likely to complete their treatment, and least likely to be referred for palliative care. These have been the patients with the worst breast cancer outcomes. These inequities are unendurable. Though we have done much within our mission to impact these outcomes, we can and MUST do more.

Although COVID-19 has forced us to temporarily close our doors to in-person programs, our hearts remain open to all affected by breast and gynecologic cancers, as well as their family members and other loved ones. As we strive to live the inclusivity of our mission, we will also strive to step off the sidelines of racism and employ resources to address the real, unmet needs that are occurring. We will not allow our words to become an echo of performative activism. We pledge to listen more and talk less, to learn more and act accordingly, and to stand with these patients in demanding a more just world with better outcomes.

We join the Greater Rochester Health Foundation and others in formally pledging our support for the Greater Rochester Black Agenda Group in their May 19, 2020 DECLARATION: RACISM IS A PUBLIC HEALTH CRISIS.

"We must always take sides. Neutrality helps the oppressor, never the victim. Silence encourages the tormentor, never the tormented."

– Elie Wiesel

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Two weeks after her fortieth birthday, Alexa’ LaDuke went for a mammogram, but not for the first time. A mammogram at age thirty-eight had been a precautionary measure for her after five years of infertility treatments. Her first breast imaging experience raised no alarms, and the time that followed passed quickly for this busy nurse and mother of two: five-year-old Kinsley, her daughter, and her three-year-old son, Kaiden. When her landmark birthday arrived, Alexa’ scheduled what was intended to be the first of many screening mammograms. But an area of concern was discovered in a place neither Alexa’ nor her doctors could palpate, and her morning appointment became a full day of additional screening procedures, culminating in a needle biopsy.

Friday, July 13th, 2018 is etched in Alexa’s memory. She remembers sitting on her deck looking at the blue sky, thinking, “Today is too beautiful for anyone to learn they have cancer. It just can’t be.” Shortly afterward, her phone rang, bringing the unwelcome news; she did indeed have breast cancer. While attempting to speak with the radiologist who had performed her biopsy, Alexa’ frantically took notes and strove to keep her voice steady so as not to alarm her children. Her mother, Gerry Bergstrom, was with her. In a five-minute conversation that turned her family’s world upside down, the radiologist advised Alexa’ there would be more medical appointments and decisions to make in the next few days than she ever thought possible.

Acting quickly, Alexa’ consulted a number of breast surgeons and plastic surgeons before selecting her medical team. Three weeks after her diagnosis, she underwent a bilateral mastectomy - removal of both breasts - with reconstructive surgery using tissue harvested from her back. Alexa’s intended three-day hospital stay was extended to six days to ensure her pain was controlled and her blood work was in the normal range. Her mother remained by her side the entire time.

Three days after she arrived home, Alexa’ received a visit from two nursing friends, who noticed her color changing. Her temperature began to rise. Gerry called Alexa’s cousins, Sue and Kurt, who came to stay with the children. Mother and daughter headed to the emergency department, where Alexa’ was admitted to the hospital. Gerry again remained in her daughter’s room, this time for five days, while Alexa’ received intravenous antibiotics for an infection, an uncommon post-operative complication. The antibiotics had the intended effect and cleared the infection completely.

When Alexa’s surgical pathology

Continued on page 22.
The Advocacy Chair Update on page 4 from our Winter 2020 issue should have included the name of Assemblyman DiPietro on the list of local assembly members support the work we do for our regional survivor community. We apologize for inadvertently omitting his name.

In March 2020, New York State, along with most of the rest of the country and world went on “pause”. Nonessential businesses closed and many of us worked, learned, and sheltered at home. But cancer does not stop because of a pandemic and neither does cancer advocacy. We advocates had to find new ways to continue our work. Like many others, we transitioned our monthly meetings to Zoom. The meeting format seems to allow for greater attendance – no commute time, no other commitments, and a desire to be with our fellow advocates, albeit virtually.

2020 is an election year, and we wanted to meet with candidates for office. Again, we turned to Zoom. Our first Zoom candidate meeting was with Nate McMurray, candidate in the June 23 special election to fill the vacant seat in New York’s 27th Congressional District. The meeting allowed the committee an opportunity to introduce the Coalition to Mr. McMurray and to hear his thoughts on health care and other relevant topics.

We are continuing our advocacy education by virtually attending the annual Advocacy Summit sponsored by the National Breast Cancer Coalition. The Summit was to have taken place in Washington, D.C. in early May. As of this writing, sessions have not begun, but planned topics include an update on the Artemis Project, which is research focused on the prevention of breast cancer and the prevention of metastasis; advocacy in response to COVID-19; breast cancer subtypes with a focus on invasive lobular disease; advocacy in a digital age; and many others. The Summit usually culminates in a day on Capitol Hill meeting with our elected officials. This year will entail virtual meetings with our representatives and their staffs.

Yes, things are different in a virtual world, but much remains the same. With the use of technology, the Advocacy Committee continues to meet our mission to advocate for and lend support to breast cancer relevant bills and public policy.

KNOW YOUR REPRESENTATIVES:

**New York State Senate**
- **Senator George Borrello**, NYS 57th Senate District
- **Senator Rich Funke**, NYS 55th Senate District
- **Senator Patrick Gallivan**, NYS 59th Senate District
- **Senator Pamela Helming**, NYS 54th Senate District
- **Senator Thomas O'Mara**, NYS 58th Senate District
- **Senator Robert Ort**, NYS 62nd Senate District
- **Senator Michael Ranzenhofer**, NYS 61st Senate District
- **Senator Joseph Robach**, NYS 56th Senate District

**New York State Assembly**
- **Assemblyman Harry Bronson**, NYS Assembly District 138
- **Assemblywoman Marjorie Byrnes**, NYS Assembly District 133
- **Assemblyman David DiPietro**, NYS Assembly District 147
- **Assemblyman David Gantt**, NYS Assembly District 137
- **Assemblyman Stephen Hawley**, NYS Assembly District 139
- **Assemblyman Mark Johns**, NYS Assembly District 135
- **Assemblyman Brian Kolb**, NYS Assembly District 131
- **Assemblyman Peter Lawrence**, NYS Assembly District 134
- **Assemblyman Brian Manktelow**, NYS Assembly District 130
  NYS Assembly District 136, vacant

The Advocacy Chair Update on page 4 from our Winter 2020 issue should have included the name of Assemblyman DiPietro on the list of local assembly members support the work we do for our regional survivor community. We apologize for inadvertently omitting his name.
An Advocate’s Odyssey
How far have Coalition advocates come and what challenges do we still face?

By Phyllis Connelly

Although the Coalition is open, access to the facility is currently limited. Programs, meetings, and activities are being conducted virtually. Staff members are working from home. Our eagerly awaited May trek to the Annual Advocate Leadership Summit in Washington, D.C., offered by the National Breast Cancer Coalition (NBCC), is postponed – thus giving me time to absorb the impact and reflect.

Much progress has been made in the understanding and treatment of breast cancer. However, much more needs to be known to prevent anyone dying of the disease.

Advocates from the Breast Cancer Coalition, an independent, unaffiliated organization, have attended the NBCC summits for twenty-three years. We listen to and converse with visionaries and leaders in the fields of science, research, medicine, journalism, public policy, pharmaceuticals, and ethics.

Here is a mere sprinkling of sessions I’ve attended:

• Herceptin – treating patients whose tumors overexpress the HER2 Protein
• Genetic Testing: Does it help to know? The risks involved
• The Role of the FDA
• The Environment & Breast Cancer: What are the links?
• Aromatase Inhibitors: Evidence and Implications
• Clinical Trials and the Drug Approval Process
• Evidence Based Complimentary & Alternative Medicine
• Nanotechnology in Imaging & Treatment
• Stem Cell Research
• Estrogen Exposure Throughout Life
• Tumor Dormancy and Recurrence
• How Can We Understand and Stop Metastasis
• Immunotherapy – What’s Happening
• Ethical Issues Surrounding Cancer Treatments
• Reading Beyond the Hype in News Media and Scientific Literature
• Informed Consent in Clinical Research
• 10 years Into the Artemis Project (www.stopbreastcancer.org)

We then spend a day on Capitol Hill meeting with our area Representatives and Senators or staff, sharing our perspective as informed survivors on public policy priorities.

Since 1992, a top priority for us has been securing continued funding for the Department of Defense Breast Cancer Research Program, or the DOD BCRP. (The reasons for DOD funding of breast cancer research is a story for another day.)

Our second priority is usually a pending bill. Presently, it is H.R.2178, also known as the Metastatic Breast Cancer Access to Care Act, which would waive all waiting periods for Medicare and Social Security Disability Insurance coverage for individuals with metastatic breast cancer.

Most recently, a high public policy priority has been guaranteed access to quality care for all.

Some notable successes in this area have been:

• The passage of The Affordable Care Act.
• The Genetic Non-Discrimination in Health Insurance & Employment Act
• The New York State Breast and Cervical Cancer Treatment Program

There are still many challenges ahead. Securing continued funding for research is an ongoing commitment. Nurturing our very good relationships with elected representatives at all levels is also vital. Ensuring past achievements remain intact is always important, as is staying patient while awaiting results of trials, tests, and FDA approval of new drugs and treatments.

Be assured, we advocates will remain diligent, persistent, and vocal in reaching our goal: to see the day when no one dies of breast cancer.

Do you want to join our efforts?
Contact us today @ (585)473-8177 or info@BreastCancerCoalition.org to learn more about our Advocacy Committee.
I love my work at the Coalition. That includes retelling the stories survivors have shared with me for inclusion in this newsletter. There’s a common response when I approach someone about sharing their story this way: “Me? My story isn’t very interesting.” By the time the words appear in print to be acknowledged by family, friends, and countless others, a realization has taken place; everyone’s story is interesting. Everyone’s story is unique and valuable.

And yet, I find myself facing the same quandary in telling my own story. Who will find this interesting? What value does it have for others? I will never know if I don’t share it.

My walk with breast cancer began on a sunny day in early May, 2004. The morning was much like any other at that time of year, bright with the promise of spring. By evening the skies had turned gray, the wind chilly, and I was left with the sensation of dangling over an abyss. In the interim, a breast lump I had been certain was a benign growth similar to those my sisters had experienced was shown to be cancerous. Life had taken a sudden detour.

One week later, I walked into the Coalition. By the time I left, I felt my feet had touched solid ground again. Ahead of me was rough terrain, but it was ground others had walked and they became my guides. Surgeries and chemotherapy consumed the better part of the year that followed, and with the support of family, friends, medical providers, and my trusted guides, I found my way through.

The years since have been punctuated by joy and growth: graduations, weddings, and children flying the nest one by one. I gratefully volunteered at the Coalition, accepted a seat on the Board of Directors for two years, and eventually joined the staff. By the time 2017 dawned, my two daughters had moved to California, one was wed, a grandson born, and we celebrated the announcement of a second grandchild — a granddaughter — to be born that summer. Life was good; it still is. But another major detour was just ahead.

My daughter, eleven weeks into her pregnancy, was diagnosed with breast cancer. Once again, I felt that abyss open. I saw her wheeled into surgery for breast cancer. I witnessed her and her unborn daughter endure chemotherapy together. Yet, ever the intelligent self-advocate, my daughter found others whose stories were similar; a community that helped guide her through. My granddaughter was born healthy and strong, and continues to thrive.

The years turned and 2019 began quietly enough. The pace of life was once again easy and familiar. It felt like an overabundance of caution to have a lump that appeared on my clavicle examined by a doctor. But with my history, it was the right thing to do. Biopsies and scans were ordered, which found that my breast cancer had spread to a number of sites within my body, including bones and thoracic lymph nodes. Once again, I was, and still am, a cancer patient.

There is no greater power on earth than story.
~Libba Bray

Continued on page 23.
Dr. Carla Falkson is a medical oncologist at the University of Rochester who came to our region from the University of Alabama at Birmingham. A practitioner whose breast cancer patients represent all facets of the disease, Dr. Falkson is originally from Pretoria, South Africa.

After she graciously consented to an interview for our newsletter, our intended face-to-face conversation became a zoom meeting due to COVID-19. Undaunted, we were able to speak in depth about a topic of interest to Dr. Falkson: HER2 positive breast cancer. This is a subtype of the disease in which the cancer cells have too much of a protein called human epidermal growth factor receptor 2 (or HER2).

Another area of interest for Dr. Falkson is translational research or, as she termed it, “...bench to bedside medicine.” She participates in a number of clinical trials and applies her knowledge to treat breast cancer patients across the wide spectrum of the disease.

Q Thank you for sharing your knowledge about HER2 positive breast cancer with our community. What work have you done regarding this disease subtype?

Dr. Falkson: I was part of the group that found the HER2 protein, which is overexpressed in about a quarter of breast cancers. It was very exciting when a monoclonal antibody called Herceptin, or trastuzumab, was developed because it targets the HER2 protein exclusively. An antibody is like a little targeted missile; it goes for a specific protein and causes cells that express it to die.

I was involved in a trial run by the Breast Cancer Research International Group, or BCIRG, a translational research organization. (BCIRG)006 was one of the pivotal trials that changed the standard of practice for the world in treating HER2 expressing breast cancer. The data were presented back in 2005. We found that adding trastuzumab to chemotherapy significantly improved the response rate for patients with early stage HER2 positive breast cancer. The data were presented back in 2005. We found that adding trastuzumab to chemotherapy significantly improved the response rate for patients with early stage HER2 positive breast cancer. Since then, I have been and am still involved in many other trials targeting HER2.

Q What does HER2 positive breast cancer means for people who receive this diagnosis?

Dr. Falkson: HER2 is one cell marker that we test for. The other two are the hormone receptors estrogen and progesterone. Patients can have hormone positive, HER2 positive disease or they can have hormone negative, HER2 positive disease. In all HER2 positive disease, we look at the size of the tumor and whether it’s spread to lymph nodes. In many cases, we can start off by giving chemotherapy before surgery and determine if the tumor is shrinking. That would be called neoadjuvant chemotherapy.

If the tumor’s already been removed surgically, we look at the pathology information and, based on that, often recommend chemotherapy along with trastuzumab. For those that are hormone receptor positive, we recommend estrogen-blocking therapies as well.

Currently, with the COVID-19 situation, we’re also looking to see if we can postpone surgeries and start treatment with systemic therapies until this pandemic is over. We try to keep people out of the hospital, basically.

One of the things we’re looking at is giving patients a drug called TDM-1. Its other name is Kadcyla. They’ve taken this trastuzumab molecule and attached the chemotherapy drug emtansine to it. The idea is that the chemotherapy delivers a bigger payload directly to the targeted cells. It’s been extensively tested in patients with stage four disease and we have some information about using it in earlier stage breast cancer. At this time, the breast cancer medical community feels it’s safe to give that as an alternative to chemotherapy plus trastuzumab for patients with early stage HER2 positive breast cancer. TDM-1 has advantages in that it causes white blood cell suppression, so it doesn’t affect the immune system the way chemotherapy does. A lot of patients do quite well and don’t need any kind of anti-nausea medications. It’s not universal that people lose their hair.

It might be a silver lining to what we’re going through now; we are forced to look for other treatments that may have less toxicity for our patients and are still as effective.

BreastCancerCoalition.org

Continued on next page.
Dr. Falkson, continued

Q How does HER2 positive breast cancer compare to other forms of the disease?

Dr. Falkson: Before we had HER2 targeted therapies, this was considered to be an aggressive disease that was not easily treatable. But since we’ve developed these targeted therapies, it’s become very treatable.

In early stage disease – that’s stages one, two, and three – a large percentage of those patients can be cured by means of combination therapy: targeted HER2 therapy, chemotherapy, and surgery plus or minus radiation therapy. However, if the cancer has spread outside the breast and regional lymph nodes – in other words, if it’s spread anywhere else in the body – that’s what we call stage four or metastatic breast cancer. Metastatic HER2 positive breast cancer is not a curable condition, but it is treatable with targeted therapies, and we’re seeing a significant improvement in median survival. This is very, very encouraging. We have treatments to keep the disease in control while extending patients’ quality of life and duration of life.

Q I’ve read recent reports about discoveries in the treatment of metastatic HER2 positive disease. Are there new treatments on the horizon?

Dr. Falkson: New drugs are being developed all the time. This is very exciting because new treatment options are being brought forward. What happens in HER2 positive metastatic disease is that you start with one kind of targeted therapy or combination of treatments and the cancer cells eventually become resistant. Then you have to find new options. That’s why it’s important, if you can’t eradicate the cancer completely, to have a pipeline of other medications that can be used in place of the ones that have stopped working.

Monoclonal antibodies such as trastuzumab are given intravenously, and there are oral kinase inhibitors that target some of those HER2 receptors as well. The most common one is known as lapatinib [Tykerb] and there’s another one called neratinib [Nerlynx].

More recently, a drug called Enhertu has gotten such good results, it was also recently approved in stage four disease. Like TDM-1, it’s trastuzumab with a chemotherapy molecule attached. The technical name is fam-trastuzumab deruxtecan.

The most exciting new agent is called tucatinib [Tukysa]. In a study called the HER2CLIMB trial, metastatic HER2 positive breast cancer patients who were previously treated with trastuzumab, pertuzumab (Perjeta) and T-DM1 received trastuzumab and a chemotherapy drug called capecitabine [Xelodra] plus or minus tucatinib. They found significant improvement in the three-drug combination. This study is being taken further by a group called Seattle Genetics.

I met with another pharmaceutical company recently to talk about a new drug in the pipeline. I think we’re going to see more of these targeted therapies coming out and being useful.

Q Do these or other recent developments have implications for those with early stage HER2 positive breast cancer?

Dr. Falkson: Traditionally, the way we’ve developed trials is to see if something works well in metastatic disease. If it does, then we think, “Wouldn’t this work even better if we gave it to patients when they have early stage disease?” Certainly in the future we will be looking at tucatinib in the neoadjuvant situation to see if it has a benefit for early stage breast cancer. There has been some indication that neratinib benefits certain patients that have hormone receptor positive, HER2 positive early stage disease.

For some of my patients with early stage HER2 positive disease, once they’ve finished their chemotherapy and trastuzumab, I’ve continued to give them a year of neratinib with hormone therapies to help prevent a recurrence in the future.

Pertuzumab, which I mentioned previously, has been used widely in early stage and metastatic disease. It binds to a different area of the HER2 protein than trastuzumab, and the two drugs are often given in combination.

When deciding which therapies to use for any particular patient, it’s always a matter of risk versus benefit. You want to prevent the cancer from coming back, but you have to match the cure to the disease.

Q What do you feel is important for those recently diagnosed with HER2 positive breast cancer to know?

Dr. Falkson: Do your homework; don’t sit back and wait for weeks or months after your diagnosis, but certainly do your homework. I usually recommend that, if patients can, they should go to a center that specializes in breast cancer and follow the recommendations of their oncologist. Ask if there are any clinical trials going on because, until we get to a one hundred percent cure rate with zero percent side effects, there are always opportunities to do research and improve what we’re doing. At the moment, ninety percent of patients with early stage breast cancer will never have their disease return, but there are still some side effects.

I think it’s important to note that, as we discussed earlier, HER2 positive breast cancer used to be difficult to treat but we now have very good treatments for it. So there’s a lot of hope. There are lots of reasons for optimism.

***
An Unexpected Blessing

COVID-19 may have limited our face-to-face interactions, but it will never dim the bright lights of those in our survivor community. Teresa Beach and I have been able to correspond by email, and here is her story.

When confusing symptoms emerged in the fall of 2013, Teresa Beach took notice but wasn’t overly concerned. It wasn’t until her annual OBGYN visit in December that she mentioned her urinary difficulties. At that visit, her sense of urgency and the sensation that she could never void completely were attributed to uterine fibroids. But on New Year’s Eve, Teresa began experiencing digestive issues. “I felt full after small amounts of food,” she recalled. Gastric trouble became a persistent, unwelcome companion. “By February, I was barely able to eat any solid food,” she recalled.

Multiple rounds of medical evaluations ensued. Teresa was seen by her primary care physician, her OBGYN, a gastroenterologist, and the emergency department of her local hospital. A colonoscopy that was ordered became too uncomfortable to continue, so Teresa was referred for a CT scan. This detected an ovarian mass, and her next consultation was with a gynecologic oncologist: a physician who specializes in diagnosing and treating cancers that occur on female reproductive organs.

On March 13, 2013, Teresa underwent a surgical procedure called a cytoreduction, more commonly known as debulking surgery, which is intended to remove as much of the mass as possible. Teresa underwent a total hysterectomy, removal of both ovaries and adjacent areas, and had ports placed for delivering chemotherapy infusions. Her postsurgical pathology report brought a definitive diagnosis: papillary serous ovarian cancer.

After one month of healing, Teresa began chemotherapy. Intravenous chemo drugs were administered through a central port and she received intraperitoneal (or IP) chemo through an abdominal port. In IP chemotherapy, which is sometimes used in gynecologic cancer treatment, chemo drugs are infused into the abdominal cavity, where they can work directly at the site of the disease.

It was a challenging regimen for Teresa. “I had twin tenth graders at the time and had plenty of parenting left to do,” she shared. “I was hopeful that I would see them through high school.”

Thankfully, Teresa’s treatment had the desired effect; her post-chemotherapy scans showed no evidence of disease. She then began a series of maintenance medications that held the cancer at bay for years, until a recent recurrence of her disease meant that she was treated once again with chemotherapy. A new maintenance medication causes some side effects, but Teresa’s post-treatment perspective serves her well. “I am able to function on this medication,” she gratefully acknowledged.

Not only has Teresa seen her twins through high school and onward, her graciousness and gratitude have been reinforced and strengthened along the way. “Absolutely everyone I knew was there for me,” she says. “Friends I didn’t know I had stepped up and

Continued on page 23.
**BREAST OR GYN CANCER 101**

These are one-to-one sessions to assist newly diagnosed individuals manage the complex tasks and emotions of a breast or gynecologic cancer diagnosis. We empower them to be self-advocates as they proceed through treatment, recovery, and survivorship. Our professional facilitators provide a safe, comfortable atmosphere where information can be absorbed and assimilated while the individual formulates a personal strategy for making informed decisions. Also valuable for a gynecologic or breast cancer survivor at any stage of their journey.

Contact us for an appointment.

**PALS PROJECT**

In this peer mentoring program, individual breast and gynecologic cancer survivors reach out to those who are more recently diagnosed, providing the reassurance of one-to-one contact with someone who’s “been there,” helping them connect with needed resources, and instilling confidence during a difficult time.

Call today to learn how to join the program and be paired with a mentor who has been there, or if you would like to become involved as a mentor.

**HEALING ARTS**

Although we remain open, for your safety we are pleased to offer all our programs virtually during the COVID-19 crisis. Our schedule remains fluid as we react to ongoing social distancing guidelines. Please contact us for program updates.

**Gentle Yoga**

Gentle Yoga includes breathing exercises, gentle and restorative yoga postures, and mindfulness exercises. Yoga activates a relaxation response and can help relieve feelings of anxiety and can help people with cancer reconnect with their body. The goal of the class is to relax, be mindful, and to improve range of motion and flexibility.

Classes are 75 minutes in length. Participants benefit most when they are present for the full duration of each class in a 4 to 6 week session of classes.

- **Rochester (1048 University Avenue)**
  - Monday morning and evening
  - Tuesday morning and afternoon
  - Saturday morning
  - Sunday morning
- **Dansville (Dansville Public Library)**
  - Thursday evenings
- **GeneSEO (Morgan Estates Community Center)**
  - Wednesday evenings
- **Geneva (Geneva Public Library)**
  - Monday evenings

**Mindfulness & Meditation**

A way of connecting with your natural state of mind and breath to calm the mind. The goal is to improve your ability to relax, concentrate, and be aware of the present moment. Classes are 1 hour and 15 minutes.

- **Rochester (1048 University Avenue)**
  - Offered Tuesday or Thursday afternoons and Saturday mornings
- **Canandaigua (First Congregational Church)**
  - Wednesday evenings

**Tai Chi**

An ancient martial art that consists of a series of small, specific movements combined with deep, relaxation breathing. Tai Chi’s goal is to improve your ability to relax and de-stress, and has other benefits such as decreasing falls in the elderly and reducing arthritis. Classes are 1 hour and 15.

- **Rochester (1048 University Avenue)**
  - Offered Saturday mornings and Thursday afternoons

**Qi Gong**

A traditional Chinese practice combining meditation, controlled breathing, and movement to balance the flow of energy (qi) within the body. The goal is to improve overall health, combat stress, and promote healing. Classes are 1 hour and 15 minutes.

- **Rochester (1048 University Avenue)**
  - Thursday afternoons or Saturday mornings

**Voices & Vision**

An engaging writing class for those interested in thinking creatively while recording personal experiences, memories, feelings, and thoughts. Each week you will respond to prompts that challenge you to reflect on the broader aspects of life’s journey. For those interested, there will be opportunities to share your writing with the group.

- **Rochester (1048 University Avenue)**
  - Offered throughout the year; runs for five week series.

Call us at (585) 473-8177 or email us at info@BreastCancerCoalition.org if you have any questions, want to enroll in a class, or want to be added to our mailing list.
Breast & GYN Cancer Group
Gather, support, network, and discuss your journey with others diagnosed with breast or gynecologic cancer. Professionally facilitated. 
No registration required.
Rochester (1048 University Avenue)
• Discussion Group: 2nd and 4th Tuesday of the month, 5:30-7:00 p.m.
• Discussion Group: 1st and 3rd Thursday of the month, 5:30-7:00 p.m.
Geneseo (Goodwill Community Room)
• Discussion Group: 2nd and 4th Monday of the month, 5:30-7:00 p.m.

Brown Bag Discussion Group
Each week a group of breast and GYN cancer survivors gather to discuss a wide variety of topics. Bring your lunch and we provide delectable treats. No registration required.
Rochester (1048 University Avenue)
• Fridays at 12:00 noon.
Batavia (First Presbyterian Church)
• 2nd and 4th Thursday of the month, 12:00 noon.

LGBTQ+ Breast & GYN Cancer Group
This monthly group offers support to LGBTQ+ breast or gynecologic cancer survivors and their partners. Professionally facilitated. No registration required.
Rochester (1048 University Avenue)
• Discussion Group: 4th Wednesday of the month, 5:00-6:30 p.m.

Common Ground:
Living with Metastatic Breast or Gynecologic Cancer
Join others coping with a diagnosis of metastatic breast or gynecologic cancer. Professionally facilitated.
Rochester (1048 University Avenue)
• Lunch Group: 1st and 3rd Thursday of the month, 12:00-1:30 p.m. Although the discussion is topic-based, all concerns of those present are addressed. Lunch and beverages provided. Registration is requested.
Rochester (1048 University Avenue)
• Discussion Group: 2nd and 4th Thursday of the month, 1:00-2:30 p.m. Share your experiences and lend your support. No registration required.

Common Ground Partners: Partners of Metastatic Individuals
Professionally facilitated group for partners/spouses of those living with metastatic (or advanced) cancer. No registration required.
Rochester (1048 University Avenue)
• Discussion Group: 3rd Tuesday of every month, 5:30 - 7:00 p.m.

Parent Networking Group
This discussion-based group supports parents who are coping with the unique challenges as they face their adult child’s breast or gynecologic cancer diagnosis. Professionally facilitated. No registration required.
Rochester (1048 University Avenue)
• Discussion Group: 1st Tuesday of the month, 5:30-7:00 p.m.

Surviving & Thriving on Aromatase Inhibitors
Through increased movement, stretching exercises, and nutrition, this ground-breaking program provides information, support, and empowerment for those prescribed aromatase inhibitors* who are experiencing joint pain or other side effects. (*Estrogen blocking medication prescribed for hormone receptor positive breast cancer.)
Rochester (1048 University Avenue)
• Wednesdays: September 2, 9, 16, October 14, 5:30 - 7:30 p.m. Registrants must commit to all four sessions.
This program is supported with funds from the State of New York Department of Health.

Young Survivor Soiree
A young survivor may identify with those who have faced breast or gynecologic cancer in the midst of a career climb, while raising children, or perhaps whose family plans have been derailed by treatment. We hold these soirees four times a year as an informal and fun way to connect with others who have walked a similar path.
Rochester (1048 University Avenue)
• Call or email today to be added to our invitation list.

Although we remain open, for your safety we are pleased to offer all our programs virtually during the COVID-19 crisis. Our schedule remains fluid as we react to ongoing social distancing guidelines. Please contact us for program updates.
Program Director Update

By Jennifer Gaylord

In February and early March 2020, our Executive Director, Holly Anderson closely monitored the COVID-19 situation. The Coalition staff could feel that change was coming. Holly prepared us for the possibility of working remotely in our homes while we considered what this would look like, given our varying duties. We considered what we would need to continue serving not only our survivor population, but those newly diagnosed with breast or gynecologic cancer during the pandemic. My first thought was, “How long would our survivors be without the community provided by the Coalition?” Our Office Manager, Michelle Lindsay, quickly garnered the tech professionals to allow staff remote access to Coalition resources. As Holly continued to monitor Governor Cuomo’s decrees, the day finally came when she directed us to pack up and set up our offices at home.

At this point, I had only a vague awareness of the Zoom meeting platform. Michelle again came to the rescue and set us up with Zoom. Over those first weeks, I walked many facilitators and presenters through test Zoom meetings. There were definitely some bumps in the road and bugs to work out, but by the end of the first week, we were almost 100 percent up and running virtually. We hold virtual staff meetings, support/networking groups, Evening Educational Seminars, Book Club, Voices & Vision, Gentle Yoga, Meditation, Tai Chi, BC 101 and GYN 101 sessions, and regional support groups and healing arts classes.

I now confidently use Zoom as a noun, verb and adverb. “I will set up a Zoom meeting.” “I will Zoom into the meeting.” “I am Zooming into the beginning of Book Club!”

Our transition to virtual provision of programs and services is nothing short of spectacular and very personal. Spectacular because we are able to provide gentle yoga, for example, to over 150 survivors in one session, including participants from all around New York State, the United States and even Bangkok! We have had support group members Zoom in from Buffalo, Virginia and Costa Rica! This transition is personal because we sit in our homes, displaying our grey roots and grown out hair, seeing family members wander through, dogs barking, and cats being cats. We are all sharing an experience we couldn’t have anticipated a few short months ago. I am so very proud of how the Coalition staff rallied to make all of this happen, including the HUGE success of this year’s virtual Pink Ribbon Walk & Run!

Please contact me to learn more about our virtual offerings at Jennifer@bccr.org.
Brown Bag Wisdom FOR STRESSFUL TIMES

Compiled by Pat Battaglia

Our Brown Bag Friday gatherings have become Zoom meetings during the COVID-19 pandemic, ensuring survivors of breast and gynecologic cancers remain connected and as supportive of one another as ever. Our very first virtual Brown Bag session was a call for email responses to a question about ways our survivor community is coping with the situation. Lovely responses came flooding in. Enjoy a mental health break by savoring some of the wisdom.

Slowing down allows one to appreciate all the little signs of spring: daffodils poking their heads up, buds swelling on the lilacs, and birds everywhere making nests. Regardless of what is going on in the world, nature prevails.

I am reading books that have been collecting dust for a while, trying to exercise every day, and go for walks. And binge-watching shows!

COVID-19 has helped us SLOW down and spend time together doing things that we have put off. Like getting more sleep!

I have been baking bread, which I love, catching up on long lost sewing projects, doing puzzles with my husband, and reading. Friends have dubbed Friday concert T-shirt day, so we are sending around pictures of ourselves in our 80’s t-shirts.

I went to the beach on a "vacation treasure hunt". I stuffed small bags into my pockets to put my treasures in. I took vacation-like photos of beautiful waves crashing onto the shoreline. When I came home, I washed my treasures and will someday make a craft with them. To self-quarantine or social distance, one can still have an adventure.

It reminds me of when I was little and had the whole day to play and decide what I was going to do. I take a nap each afternoon, because I do wake up in the night with some scary thoughts and anxiety. Then the morning comes and there is a new day.

We are having an epidemic of kindness towards each other. This is an epidemic I hope will last well beyond COVID-19!

Here are my ways of coping:
• Stay off the internet except for a quick check-in a couple of times a day.
• Clean up the gardens, a cupboard, or a drawer.
• Read a good book.
• Bake! If you have a favorite cookie recipe you haven’t used in years (and you have the ingredients) go ahead! The stress will burn calories.
• Write some letters the good old-fashioned way... imagine the surprise!
• Stay in touch with those you love through technology such as Facetime, Skype, Zoom, Team.

I am playing CDs, which are compilations of music from the 50’s thru the 80’s my husband made. I dance to the music in my living room. Good exercise and good memories!

JON’S BLUEBERRY CUCUMBER PASTA SALAD

From F. Olliver’s website: folivers.com
This cool summer salad is easy to make, tastes fresh and flavorful, and keeps well - it’s perfect for summer picnics!

Salad
1 pound Flour City* Fresh Cucumber Gnocchetti or any short cut pasta, cooked al dente (about 5-7 minutes)
3 cucumbers, peeled, halved, seeded, and sliced
1 pint fresh blueberries
3 tablespoons fresh mint, thinly sliced
4 scallions, thinly sliced
1 cup feta cheese

Dressing
¾ cup extra virgin olive oil: F. Oliver’s Fresh Pressed Meyer Lemon, F. Oliver’s Garden Fresh Gremolata, or medium single varietal EVOO
¼ cup white balsamic: F. Oliver’s Lemon Bouquet, F. Oliver’s Aromatic Oregano, or F. Oliver’s Classic White Balsamic
1 tablespoon honey
2-3 tablespoons freshly squeezed orange juice

Combine cooled pasta with the fresh ingredients. Mix the dressing, toss with the salad, add salt and pepper to taste. Serve cold or at room temperature.

*flourcitypasta.com

BreastCancerCoalition.org

Summer 2020 • 13
More than $900,000—that’s how much the Coalition has given since 2003 to support breast cancer research in our region.

This year, thirteen research grant proposals were submitted for funding through the Coalition’s Research Initiative. A review panel composed of eight scientific researchers and seven survivor/advocates selected the proposals to be recommended for a 2020 Pre- and- Post Doctoral Trainees/Fellow Grant of $25,000 and a 2020 Faculty Grant of $50,000. These selections were then presented to and approved by the Board of Directors. Including this year’s awards, the Coalition has now provided $926,125 in funding to researchers in Upstate and Western New York.

The recipients and their proposals represent a cross-section of both research backgrounds and topics:

- **Matthew Lee Tan**, recipient of a trainees/fellow grant, is a fourth-year PhD student at Cornell University. He is the son of Cambodian immigrants and a first-generation college student. His study, titled “Investigating the Role of Metabolism and the Perivascular Niche on Breast Cancer Stem-Like Cell Properties,” will examine how endothelial cells and nutrient transport in perivascular niches (regions near blood vessels where cancer stem-like cells [CSCs] are frequently found) can affect CSC characteristics and metabolism. Results of this work will help inform new strategies to target CSCs with the potential to prevent metastasis, lead to new therapeutic approaches, and ultimately improve patient outcomes.

- **Dr. Isaac Harris**, an Assistant Professor at the University of Rochester Medical Center and Associate Member at Wilmot Cancer Center, is the 2020 Faculty Grant Recipient. His entire research career has been focused on breast cancer, and his Coalition-funded study will focus on “Uncovering the roles of extracellular glutathione in triple negative breast cancer.” His lab has discovered that triple negative breast cancers (TNBC) rely on antioxidants to survive. They hypothesize that TNBC captures antioxidants in the blood, and uses these resources to grow and survive drugs intended to kill them. The Harris Lab plans to find ways to kill TNBC by blocking the proteins that liberate circulating antioxidants. The studies have the potential to benefit patients with TNBC.

The Coalition’s research grant program, unusual for a non-profit “grassroots” organization, began in 2003 with a single grant of $25,000. Recipients are affiliated with and conduct their projects in institutions located in the Coalition’s coverage area. Through our funding, recipients are given the opportunity to generate data needed to apply for larger grants from such major organizations as the Department of Defense and the National Institutes of Health.
THINK BEFORE YOU PINK

In response to growing public concern about the number of pink ribbon promotions and consumer products, early leaders of the Coalition participated in the development of an initiative called Follow the Money. Launched in 2002 and eventually renamed Think Before You Pink, the project is now overseen by the national organization Breast Cancer Action and receives our ongoing support. The initiative offers four essential questions for consumers to ask when considering where their donations and purchases will have the most meaningful impact.

1. **Does any money from this purchase go to support breast cancer programs? How much?**

   The pink ribbon is ubiquitous. It’s an easily recognized but unregulated symbol. It’s not always clear how much, if any, of the money consumers spend on any particular pink ribbon product will actually support breast cancer programs or research. Read the fine print! Instead of paying extra for a pink-ribbon product, consider giving to the local charity of your choice, where your dollars will have the greatest impact in your own community.

2. **What organization will get the money? What will they do with the funds, and how do these programs turn the tide of the breast cancer epidemic?**

   Before making a purchase, check the recipient organization’s website. If its mission is unclear (for example, “raising awareness” is a vague term), its activities out of line with your own personal values, or you can’t tell what the organization does, reconsider your purchase.

3. **Is there a “cap” on the amount the company will donate? Has this maximum donation already been met? Can you tell?**

   When companies set a maximum donation from the proceeds of a pink ribbon item, consumers have no way to know when that limit has been met, even though the product often remains on store shelves and continues to be sold. Consumers may think they are supporting a good cause when, in fact, the producer of the product is profiting.

4. **Does this purchase put you or someone you love at risk for exposure to toxins linked to breast cancer? What is the company doing to ensure that its products are not contributing to the breast cancer epidemic?**

   When scientific evidence indicates a link between certain chemicals in some consumer products and breast cancer, it is unethical for companies seeking to build a reputation of concern about the disease to market pink ribbon products containing these substances. Since many of the products in question are personal care items such as cosmetics and perfume, it helps to have an unbiased resource when considering these purchases. The Environmental Working Group is one such resource (ewg.org).

Breast Implant RECALL Update

BIOCELL textured breast implants and tissue expanders, manufactured by Allergan, are just one of many types of implants used in certain breast reconstruction procedures after a mastectomy. They were recalled on July 24, 2019 due to evidence showing this type of implant is linked to an increased risk of breast implant-associated anaplastic large cell lymphoma (BIA-ALCL). On June 1, 2020, Allergan launched External Link Disclaimer, a campaign to contact patients who may not be aware of the recall.

BIA-ALCL, a rare type of non-Hodgkin’s lymphoma, is most often found in the scar tissue and fluid near the implant. In the majority of cases, surgery is curative, although more widespread disease has occurred in a few. As of January 24, 2020, approximately 307 cases were recognized in the United States. There are 33 known deaths worldwide from the disease.

Most often, the signs of BIA-ALCL are persistent swelling or pain around the implant, but patients should report any changes in the area to their plastic surgeon or another health care provider. Due to the low risk of developing BIA-ALCL, preventive removal of the implant is not recommended.

People who are not aware of the BIOCELL recall or do not know the type of implant they have or their implant history, should:

* Go to www.BIOCELLinformation.com to determine if the company has their implant information.

* Contact their surgeon or hospital where they received implants to determine if the surgeon or hospital has records of their implant information.

The 19th annual Pink Ribbon Walk & Run became a virtual event this year due to the COVID-19 pandemic. More than 1,100 participants registered for the transformed event, coming together over Mother’s Day Weekend while staying apart and practicing social distancing guidelines. Together, they raised over $155,000 in profit to support the Breast Cancer Coalition!

Anyone anywhere was able to join the fun safely this year, and the event included participants from our 10-county Finger Lakes region, from 20 states throughout the country, and even Canada! They walked and ran in their neighborhoods, on hiking trails, in parks – in countless different places. Many walkers and runners captured the day in photos and shared them on their social media platforms or with the Coalition – creating a real sense of community by virtual means.

Cancer does not stop because of COVID-19. Neither does the Coalition. And neither do you! All the funds raised through the walk & run will be used to provide education and support programs for survivors, to support advocacy efforts and to promote research on breast cancer.

Thank you to everyone who participated in the 2020 VIRTUAL Pink Ribbon Walk & Run!
TOP 5 INDIVIDUAL FUNDRAISERS
1. Holly Anderson $8,061.00
2. Sloane Miller $7,705.00
3. Patti Cataldi $3,645.00
4. Melisande Bianchi $3,200.00
5. Dawn Lee $2,945.00

Number of participants: 1,102

36 Individuals raised more than $500

One Lucky Guy
Ralph Whiteman

200+ participants from our 9 county region (outside Monroe County)

Jber, Alaska
Farthest away participants

TOP 5 TEAM FUNDRAISERS
1. Sloane’s Squad 2020 $7,885.00
2. Team BFF $5,195.00
3. #TeamPamPolashenski $3,310.00
4. One Webster $2,470.00
5. Mama Bear’s Cubs $2,205.00

Quebec, Canada
Countries outside U.S.

We are grateful for the support of our sponsors:

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Fp Wellness
Mona Moon Naturals
Osborn Reed & Burke, LLP

20 States represented

93 Number of out-of-state participants

One Lucky Guy
Ralph Whiteman

28 members
Biggest Team: Quatela Center for Plastic Surgery

93 Number of out-of-state participants
FROM THE REGIONAL SERVICES DIRECTOR

Updates from the Region

By Miriam Steinberg

On Tuesday, March 10th, eighteen advocates set out before dawn to travel to Albany in support of the Breast Cancer Coalition’s regional programming. We had survivors, supporters, Board members, staff, and regional program participants.

We spent the day bringing awareness of our work in the Finger Lakes and Central NY area and building relationships with these elected officials and their staff in an effort to brainstorm the most effective ways to continually get the word out about our programming.

We also thanked our regional Senators and Assembly members for the diligent work they do to ensure funding for our regional programming and also to ask for continuation of that funding to keep the programming going.

We would like to extend our appreciation and thanks to the following elected officials and their staff members for taking the time on March 10th to meet with us regarding the work we do for the Upstate survivor community.

- Lieutenant Governor Kathy Hochul
- Senator Pamela Helming
- Senator Patrick Gallivan
- Senator Gustavo Rivera (Chair of the Senate Health Committee)
- Senator Julia Salazar (Chair of the Senate Committee on Women’s Health)
- Assemblyman Harry Bronson
- Assemblyman Richard Gottfried (Chair of the Assembly Health Committee)
- Assemblywoman Melissa Miller
- Assemblywoman Marjorie Byrnes

Keep an eye on the website calendar for updates and schedules for the regional programming and always feel free to email or call me if you want further information about any particular session.

(585) 473-8177 x 310
Miriam@BreastCancerCoalition.org
L-R front at table: Barb Legere, Silvia Gambacorta, Ali Dennison, Rebecca Solomon, Melissa Bianchi, Deb Bishop, Owen Toale; L-R back: Betsy Crumity, Jennifer Gaylord, Peg Jacobs, Patti Cataldi, Phyllis Connelly, Kathy Cunningham, Deb Hennekey, Senator Pamela Helming, Bethann Miller, Holly Anderson, Miriam Steinberg, Lori Meath

L-R front: Silvia Gambacorta, Barb Legere, Sherri A. Salvione Legislative Associate Office of Assembly Member Richard N. Gottfried, Betsy Crumity; L-R back: Jennifer Gaylord, Owen Toale, Holly Anderson, Miriam Steinberg, Lori Meath, Deb Bishop

L-R front: Rebecca Solomon, Phyllis Connelly, Assembly woman Melissa Miller, Silvia Gambacorta, Barb Legere; L-R back: Jennifer Gaylord, Kathy Cunningham, Patti Cataldi, Deb Hennekey, Holly Anderson, Deb Bishop

L-R Bethann Miller, Deb Hennekey, Assemblyman Harry Bronson, Lori Meath, Miriam Steinberg, Betsy Crumity

Holly Anderson and Assemblyman Brian Mantelow

L-R front: Peg Jacobs, Patti Cataldi, Phyllis Connelly, Ali Dennison, Rebecca Solomon; L-R back: Bethann Miller, Kathy Cunningham, Senator Patrick Gallivan, Melissa Bianchi, Deb Hennekey
With A Little Help From Her Friends

I sat down with Pam Wolf on Thursday, March 5 to interview her for this story. We met following the monthly meeting of the Dansville Coffee Group, an informal gathering of women from the Dansville area who are survivors of breast, gynecologic, and other cancers. This informal support group began after many of the participants met at a Gentle Yoga session provided by the Coalition in Dansville. On this particular morning, fifteen women had gathered at the coffee shop for the meeting. Unfortunately, due to the COVID-19 situation, they have not been able to meet since. But as many of us now know, support and friendship can't be stopped by a pandemic. The group members stay in contact, although now it’s by phone. I mention the coffee group because these women play a significant part in Pam's story.

In December of 2018, Pam woke in the middle of the night with a burning pain under her right arm. Reaching up, she felt a lump in her armpit. The next morning, she contacted her primary care physician. Upon examining the lump, the doctor referred Pam to a surgeon who recommended a biopsy. She was able to schedule her biopsy within a week. On December 27, she received the results; Pam had breast cancer in her lymph node only. She is one of a very small percentage of patients diagnosed with breast cancer who never experience a lump or any other symptoms in the breast; the condition is called hidden or occult breast cancer. Pam’s doctor referred her for a PET scan, which showed no tumors in her right breast.

Pam remembers feeling unable to fully comprehend what her doctor was saying; it took a while for the news to sink in. When the doctor asked if she had any questions, Pam replied that she didn’t even know what to ask. Her doctor went on to explain about the medical team that would be working with her and asked her to be sure to let him know if she had any questions. The fact that Pam now had a ‘team of doctors’ felt overwhelming; she didn’t quite know what that meant. Pam’s doctor was right there with answers, explaining that her first step would be a consultation with a medical oncologist to discuss the initial phase of her treatment.

Pam didn’t have to wait long; her medical oncology appointment was scheduled within a week. During that visit, she learned her treatment would begin with sixteen rounds of neoadjuvant chemotherapy. (Neoadjuvant treatment is intended to shrink a tumor before the main treatment, which is usually surgery.) A week later, a port was inserted to facilitate chemotherapy infusions, which began in February of 2019.

Fearful when she heard about the side effects of chemo to be rough, Pam recalls that, at the time, she didn’t know anybody who had breast cancer; no family member nor any friends. She wasn’t sure who to talk to for support. It was during this time that Pam began attending the coffee group mentioned earlier. As one with a naturally quiet demeanor, Pam listened intently without saying much for the first couple of meetings. But it didn’t take her long to “find her groove”- the gatherings can get animated and boisterous at times - and soon Pam started sharing her story and asking questions. She had discovered a community of women willing to share their experiences and their support. These women stepped up to drive Pam to her treatments and stayed with her so she wouldn’t be alone. They have done this for many other women in the group as well.

Although she found the side effects of chemo to be rough, Pam eventually finished all sixteen rounds of chemotherapy. Besides losing her hair, she experienced some cognitive issues, sometimes referred to as “chemo brain,” a condition that has been improving since chemotherapy ended. Another side effect has been lingering neuropathy in her hands and feet.

A bright spot during this time was a helpful connection Pam formed with one of her chemo nurses. Without him, Pam said, she wouldn’t have gotten through it. For her, the walk into the hospital and to the office was, emotionally, the hardest part. This nurse kept an eye out for her and offered encouragement, reminding her that she could do this. It was just the kind of support Pam needed.

It was difficult for Pam to get used to changes in her appearance. Her hair began falling out about two weeks...
Pam now has people to call who understand what she’s going through; that, for her, is huge.

One thing that has brought joy to Pam during all this came from her oldest daughter Krystina, who works for American Airlines. The airline, in collaboration with a group called Stand Up to Cancer (SU2C), was launching a promotion to provide a once-in-a-lifetime opportunity to add a loved one’s name to a plane in honor of those who are cancer survivors, currently fighting cancer, and those who have been lost to the disease.

Those who donated to Stand Up To Cancer (SU2C) during the month of July 2019 could add the name of a person they stand up for to an American Airlines Airbus A321. The plane, which was wrapped with a special SU2C design including the names submitted, was ready to fly in November 2019. Krystina submitted her mother’s name, and it is now on the left wing. Pam received a model of the plane, which she proudly displays.

Still adjusting to her new normal, Pam is not walking as much as she used to because of neuropathy in her feet and has not yet regained her pre-diagnosis energy reserves. Although anxious to resume her normal level of activity, she’s trying to be patient while waiting the year or so her doctors have said it may take for that to happen. Pam feels she’s not quite herself yet, but she’s getting there with a little help from her friends.
BreastCancerCoalition.org

Alexa’ LaDuke continued from 3

report became available, it showed estrogen and progesterone were growth factors in her tumor. This meant her cancer would respond to targeted hormonal therapies. A lymph node removed during surgery was also found to contain cancer cells. Chemotherapy and radiation, which had been on the radar for Alexa’ and her doctors, became strongly recommended.

Chemo came first. The most challenging side effects for Alexa’ were bone pain and fatigue, so she hired a nanny to help ensure her children’s lives and activities would remain as close to normal as possible. A cold cap, which she opted for during her chemo infusions, helped keep her hair loss at around fifty percent; an amount noticeable to her but barely detectable to others. Knowing that the success of cold cap therapy varies widely from person to person, Alexa’s choice was driven by the desire to maintain as much normalcy as possible for Kinsley and Kaiden, including their mom’s appearance. For her, it was helpful.

While recovering from her hospitalizations, Alexa’ found it difficult to hear her children’s laughter drift in through her open bedroom windows and not be part of the fun. She received photo texts from close friends, Monika, Nicole, and Giovanna, who graciously took her kids on adventures. But feelings of distance from her children’s lives were, for Alexa’, hard to bear. Her first post-op goal was to be in the driveway when Kinsley left for her first day of Kindergarten. Not only was she the driveway, Alexa’ went to orientation and on a field trip in the middle of chemo.

After chemotherapy was finished, radiation therapy came next for Alexa’. The weeks of treatments meant daily trips to the cancer center, and Alexa’ is grateful she did not experience any side effects from this treatment. Gerry witnessed the emotional moment when her daughter rang the bell in the waiting room of the infusion center signifying the end of active treatment. (Read on for her words about that experience.

Ten months after her diagnosis, Alexa’ underwent a complete hysterectomy to reduce the risk of recurrence of her estrogen-based cancer. That risk is further reduced by a daily oral medication, Tamoxifen. She also receives monthly infusions of the bone-building agent, Zometa.

Shortly after her diagnosis, close childhood friends Nicholas Haralambides and his sister, Jenn, steered Alexa’ in the direction of the Coalition, where she met with our Director for a Breast Cancer 101 session. After being matched with a mentor through our PALS program and attending support groups and Healing Arts classes, Alexa’ has forged deep connections within our survivor community that sustain her to this day.

Sadly, Alexa’s marriage ended about a year after she was diagnosed. But she is not flying solo. She, Gerry, Kinsley, and Kaiden – along with their two beloved dogs - form a complete household and enjoy life to the fullest. The many life changes she underwent prompted a career change for Alexa’, who retired from nursing to open her own interior decorating business, Style of Serenity (www.styleofserenity.com).

In a heartfelt journal entry, Alexa’ wrote, “I drive and think of things pre-cancer and look back upon them with such rose colored glasses…all I think is how I want to go back to those carefree days where my biggest worry was how to accomplish all I had to do that day…Those are the days I thought were so stressful. The days I wished would pass quickly. Now I realize that those were the days to love and to embrace.”

Alexa’ now embraces every day.

***

Ringing the Bell

By Gerry Bergstrom

Any time my daughter heard the bell ring at the cancer center, she lowered her head and would refuse to look up. Alexa’ hated the place. She hated the parking space that said "Reserved for Patients." She hated the sign on the building that said "Cancer Center." She averted her eyes from the bald heads in the waiting room. Every three weeks, she would be there for chemotherapy infusions, and after months of those visits, she went back every day, five days a week for nine weeks for radiation therapy.

On her good days, Alexa’ felt one of two things: she either refused to believe she had cancer or was filled with optimism she would beat it. On her bad days, she feared she would die regardless of what she or anyone else did. That bell bothered her even on her good days, but especially on the bad ones; the way the people clapped as a patient rang it and how everyone would "high five," and hug one another. She thought it was dumb to celebrate being done with chemotherapy or radiation. As only her mother would understand, Alexa’ was too afraid to believe that she would ever really be cancer free.

She sat in that waiting room week after week and looked down at the floor, or buried herself in a magazine that she wasn’t really reading, ignoring the bell and the people clustered around the patient ringing it. Then one day, lost in thought as she sat waiting to be called back,
We celebrate all who set an unwilling foot on this path, along with our friends and supporters.

FRIENDS REMEMBERED

Quintina (Tina) Bond
Marlene Caroselli
Lisa (Lee) Mills-Runyan
Tom Cook
Joseph Errigo
Betty Gleason

Jennifer Gravitz
Linda MacDonald
Christine Martin
Gail Palluconi
Patricia Woodin

Pat Battaglia continued from page 6

Approaching the door to the infusion center for my first treatment felt at first like walking toward yet another abyss. Instead, beyond that door were compassionate nurses who treated me with kindness, concern, and respect. They continue to do so and always welcome me cheerfully for each infusion.

As the second year of my walk with metastatic breast cancer unfolds, I cannot say this will ever be easy. But I will never be alone. My family and friends walk with me. My colleagues at the Coalition do likewise. And my Common Ground Peeps are a lifeline. Their stories are uniquely their own, but we share a common experience – the ups and downs, the gains and losses, the outrageous joy of being alive – together.

I no longer think in terms of abyss, or emptiness, in the face of very difficult situations. It is times like these when community matters most. Allowing our support communities – or our networks, tribes, or any name we choose to give them – to grow and evolve according to our changing needs is a survival mechanism. This is just the sort of community encouraged at the Coalition in so many different ways, and for me, it has opened a door into a welcoming, safe space. At this time, with the threat of COVID19 before us, that space is virtual. But it is real, nonetheless.

We open the door to community by telling our stories. Please share yours. Contact me at pat@bccr.org.

Teresa Beach continued from 9

helped our family.” Countless friends, old and new, rose to the occasion. They organized meals, transported Teresa to and from treatment, and ensured the twins had rides to and from their sports and music commitments. “Don’t be afraid to accept help,” she would advise others on a similar path.

“I have experienced a lot of losses,” Teresa shared. Her strength, stamina, and yes, her hair are among those losses, but are slowly returning. “And there are a lot of blessings. Gratitude for each day is an unexpected blessing.”

Ringing the Bell continued from previous page

Alexa’ looked up and saw the smiles on all the people in the waiting room. She suddenly realized that the bell didn’t mean a cure. The bell didn’t mean that everything was going to be okay for all who rang it. The bell meant hope. Every time someone rang it, the patients still in treatment were filled with hope that they too would one day be able to ring that bell.

Finally, that day came for Alexa’. By then, she had decided the parking space that said “Reserved for Patients,” belonged to her, and would joke when she pulled in and someone was in “her spot.” She now believed that the people working in that building with the "Cancer Center" sign were wonderful. When she checked in, she would talk with the receptionist like they were old friends. People knew her, said hello to her in the hallways, and asked how her children were. It was suddenly a happier place for her. Alexa’ rang that bell after her last chemotherapy treatment with zest for life. She invited her children to help her ring the bell again after radiation ended, full of hope that everyone in the waiting room understood she was ringing it for HOPE.
DEVELOPMENT/SPECIAL EVENTS

DON’T STOP

Valerie J. Pasquarella, Development Director

When COVID-19 arrived in Western New York in mid-March and nonessential businesses began their (hopefully) temporary closures, and we received word about the prohibition of large gatherings, fundraising professionals started panicking. Many nonprofits, including the Coalition, had fundraising events scheduled for April and May. We also had spring appeal mailings planned. Perhaps major gift solicitations were on the table. What should we do? It wasn’t an easy question to answer. We could look to other crises such as the 2008 recession or the attacks on September 11th, but this wasn’t quite the same. The future seemed very uncertain.

So we started talking to each other. Brainstorming. Attending webinars and Zoom meetings with experts and consultants. One only had to listen to two or three colleagues before a theme began to emerge: Don’t stop trying to raise the funds necessary to keep going.

DON’T STOP because our mission is still vital.

DON’T STOP because our communities still need our programs and services.

DON’T STOP because donors still care about organizations and want to help.

For the Coalition, this meant we still mailed our spring appeal. We transitioned our 19th annual Pink Ribbon Walk & Run to a virtual event. We participated in Giving Tuesday Now. We did this because CANCER DOESN’T STOP, AND NEITHER DO WE. The funds provided through our appeals and events are vital to our ability to fulfill our mission and to support our survivor community.

Thank you to everyone who joined us in saying, “I’m not stopping,” and either made a gift or joined the virtual walk and run or did both. We deeply appreciate your commitment and generosity – NOW MORE THAN EVER.

A Prayer

The Voices of Survivors

I take delight in tapping my finger on the white ceramic bowl

A choir of birds in the brightening sky

I need no other music

So full of spring in my mind

The glory of the sun

The light is different

It is new every day

There is so much else happening

I instruct myself to seek stillness

My prayers are songs

My prayers are made of quiet

It inspires me to create more

My prayers are made of laughter and smiles

My prayers are made of the most delicate strands of hair

My prayers are made of stone-cold silence

Every day I see the light stream through

Sounds and sights bring comfort

Sounds and sights bring fear

My prayers are made of women in community who soften my sharp edges teach me other ways to react let her know she is not alone either Dawn finds its way It is new life and it makes me hopeful I pray that I find joy in the journey of this new day I pray humans to awaken.

Created by Ren vanMeenen, Voices and Vision facilitator, using the words of Voices and Vision participants.
PALS Update

By Pat Battaglia

As I write, the COVID-19 crisis is heavy on the minds of everyone I know. The fact that this has affected every person on the planet to one degree or another is mind-boggling to me. Among those most significantly impacted are people facing a recent cancer diagnosis. With our health care systems strained to the limit, questions about scheduling surgeries and treatments abound; questions that were unthinkable a few weeks ago. For instance, who could have predicted that those entering the hospital for lifesaving procedures would, for safety’s sake, ever need to leave their loved ones behind at the door? At stressful times, a simple hug goes a long way. Yet our necessary and lifesaving social distancing measures drastically limit that. How does one cope with such a scenario?

In these unforeseen times, our PALS mentors have stepped up to bat for those newly diagnosed with breast and gynecologic cancers. They “keep on keeping on”, reaching out to individuals making surgical and treatment decisions during this pandemic. Although people facing a cancer diagnosis during this pandemic are dealing with unprecedented levels of uncertainty, our mentors have continued to listen and respond to their concerns with compassion and insight. Under these difficult conditions, PALS mentors haven’t missed a beat. Time and time again, they have shown they are just as adaptable, empathetic, and genuinely helpful to their mentees as they have always been. I am humbled and grateful to work with such a group of dedicated, caring volunteers who give so generously of themselves.

Whatever changes this crisis has brought, one thing remains constant: our PALS mentors are a group of individuals with deep resources of inner strength. Since the inception of this program in 2008, they have reached out to the newly diagnosed and shared stories of hope and healing. And nothing, including a pandemic, can deter them.

Jennifer Ulrich
Making a Difference, Stitch by Stitch

Her survivor’s story has graced the pages of this publication. Her exquisite quilting has added a compassionate touch to PALS paks and encouraged generous donations at our ARTrageous Affair. Her words of gentle wisdom and uncompromising self-advocacy have lifted spirits and inspired many of her fellow Brown Bag attendees. As a PALS Mentor, her calm, steady presence has offered hope to the newly diagnosed. And, in the face of the COVID-19 pandemic, Jennifer Ulrich has worked tirelessly to make a difference for many in our community; she has stitched together a countless number of face masks for distribution in our PALS paks, for our staff members, and for many others.

Jen, as we know her, was one of the first survivors who Ali Dennison, our Program Assistant, came to know after starting her position at the Coalition two years ago. To their mutual surprise, Jen and Ali realize their mothers, both of whom were from England, had been friends. “Jen is one of the kindest, talented, and most giving people I know,” Ali said. “She so thoughtfully shares her gifts by making beautiful quilts for survivors. I love when she brings these masterpieces to show us, and I enjoy listening to all the details that went into making them. She often attends our Brown Bag Friday group and has the most insightful things to say. I always learn something new from her. Since the coronavirus pandemic began, she continues to go above and beyond by making masks for any survivors that need them. When I wear mine, I feel like Jen is right here with me keeping me safe and protected. Jen is truly a kind soul.”

Jen’s bright thread of compassion is woven throughout our survivor community and in our hearts at the Coalition.

Thank you, Jen!
OUTREACH DIRECTOR UPDATE

For the Coalition, as for so many others, March came in like a lamb. Our programs were humming along, we were gearing up for the Pink Ribbon Walk and Run (our largest fundraiser of the year), and I was gathering volunteers for the ten day Lilac Festival.

And then came COVID-19.

In those early days, I was struck by a stunning question: can I do my job? Can I really be effective at outreach if I can’t go anywhere? In the absence of the Lilac Festival; in the face of our Walk and Run becoming virtual; in light of the suspension of all health fairs, conferences, lunch and learns, newsletter deliveries, and community fundraisers...was Community Outreach relevant?

That answer also became quickly clear. We need MORE THAN EVER to reach out to the community around us. We need to spread the word that we are here and “open” virtually. We need people to look toward supporting our Mission beyond these confounding days; to ensure next year’s Research Grant Award, to grow our support and Healing Arts programs, to continue our advocacy efforts, to educating our greater community, to spread the word about all of the above. We need to thank our community for all they have done and tell them how they can help us in the future.

We need our beloved volunteers to continue to “volunteer” by registering for the virtual walk; by sharing the message that we ARE open and available to anyone who needs us, even now; by telling your faith community, book club, wine group, and exercise friends how much we need THEIR help right now.

The longer this COVID-19 situation goes on, the more important outreach is to us and to our community, and the more important YOUR part is in sharing the message!

LEARN MORE ABOUT OUTREACH

(585) 473-8177 x 304
Lori@BreastCancerCoalition.org

ALL FOR MOM

We especially cherish the gifts we receive from young people in our community.

As Peter D looked toward his upcoming 11th birthday, he knew he wanted to include his Mom in his celebration. Peter’s mom faced breast cancer in 2017, and it had been a tough time for their entire family.

In support of the programs the Coalition offers for people like Peter’s mom Anne and the local research we fund, he decided to ask for gifts to support that work in honor of his mother.

Peter, we thank you and your friends for your donation of $100. What a great “reverse” birthday gift!

WORKING HARD, PLAYING HARDER

For the third year, the Monroe County Fire Bureau Hockey team has dedicated the proceeds of their February tournament to the Breast Cancer Coalition. Bundled against the frigid indoor temps of the Lakeshore Ice Arena, friends and families of these firefighters (some of whom had worked all night!) gather for a spirited, fast-moving contest against rival teams from Auburn NY and the Rochester Americans Warrior Hockey veteran group on February 8.

Though it would be hotly debated, there were no “losers” on an afternoon of competition, food, and raffles. And the real winners- the survivor community of the Coalition, in whose honor a gift for $3000* was presented by event coordinator/Firefighter Michael Stoerger. Thanks to Mike, his hardworking family, and the incredible generosity of all who attended.

*We were also thrilled to receive a donation directly from the Rochester Americans Warrior Hockey team for $250!

Continued on next page.
FOR THE LOVE OF AMY

Amy Schnitzler was a light in the lives of all who cherished her energy, her sassy wit, her sly humor and her unflinching, un-failing honesty in the face of the cruelty of a cancer diagnosis at 26 years old. Certainly no one misses irrepressible Amy more than her loving mother, father and brother.

Prior to Amy’s death in December, her dad Gary Schnitzler had planned a musical fundraiser to assist Amy with the burden of her frequent out of area trips for treatment. A talented and busy musician, Gary rallied his musical support system to present an evening of great music, food, and friendship.

Amy’s spirit was with the event on a snowy, blowy Saturday in January. Gary offered the event as a tribute to those who had helped Amy along the way of her four years of living with cancer, and a donation of $788 was made to the Breast Cancer Coalition as well as one to METAvivor.

Amy was a gift to all of us!

THE POWER OF PINK CAMPAIGN PIC

In recognition of breast cancer awareness month, Brighton Collectibles pays national tribute to those facing breast cancer with their month-long Power of Pink campaign. Limited edition creations of jewelry and accessories are offered with apportion of each sale supporting breast cancer research. Our local Eastview Mall store direct their store’s campaign toward education of its primarily female customers, and partners with the Breast Cancer Coalition to highlight our own LOCAL research initiative.

This year, the Eastview crew raised $602 to support our work.

HEROES IN IRONDEQUOIT

Irondequoit’s St. Paul Fire Department hosted a family day in October, attracting families from the area to the House to enjoy BBQ, tours, games, and information. Special T shirts commemorating the day were also sold. The celebration was part of a larger effort dubbed Badges Against Breast Cancer.

In cooperation with the Irondequoit Ambulance, Inc., Irondequoit Police Department, Laurelton Fire Department, Point Pleasant Firemen’s’ Association, Ridge Culver Fire Department, and Sea Breeze Fire Department, an amazing $2195.76 was raised from this and a variety of events to honor survivors in our area.

BIG RESULTS FOR A LITTLE LEAGUE

The Fairport Little League organization is a “family.” Vice President of Operations Lou Bianco is a beloved member of that family and is also the husband and father breast cancer survivors Diane Bianco and Rosemarie Morrison, diagnosed with breast cancer in 2017 and 2018 respectively.

The organization recognized and honored these women and many more friends and family by raising $1000 for the Coalition, which was presented to us by Lou and Rosemarie.

We are so grateful to the young players of the League for their efforts, supported by your wonderful families and the support of their families—at home and on the field!

* We apologize for a previous erroneous version of this piece!

FUTURE FRONT LINE NURSES

It was a pleasure to present to and speak with the LPN students of SUNY Brockport’s Nursing program at the REOC in downtown Rochester! As they perfect their clinical skills, they also seek to understand the emotional and practical challenges of their future patients and their families who will face a breast or gynecologic diagnosis.

As a gesture of support for what the Coalition provides in the community, they made a donation of $100.

Planning a fundraiser? For guidelines and assistance contact Lori at (585) 473-8177 x 304 or Lori@BreastCancerCoalition.org.
“ROC”ING THEIR SOUL IN ROCHESTER

Malena and Joe Guadagnino are a young couple with passion; most of all passion for family, friends, fitness and great food. Their Webster business, ROC & Soul Fitness, gives them the opportunity to combine all of these for the good of the community they love.

On a chilly Sunday in January, they created and hosted a “pop-up charity dinner” to benefit our Coalition. Their gym was converted to a cozy Italian venue, awash with soft pink and blue light and filled with the smells of a homemade Italian meal. Guests dined at cloth-covered tables, enjoying friends, wine and fine food in a beautifully decorated setting.

Family friend and active Coalition volunteer Margie Micca spoke to the crowd to share the Coalition’s gratitude and her own experience with the Coalition.

This magical evening resulted in an incredible gift of $2500 to our work. Thanks to this dynamic couple and their caring community!

A BENEFIT BAZAAR

We were honored to receive the proceeds from a booth at the Ontario United Methodist Church’s November bazaar. Thank for your gift of $243, and your support!

A LONG-STANDING TRADITION

The Churchville-Chili Saints Hockey team once again took to the ice on the day after Christmas for their holiday tournament. Pink the Rink has been a Churchville tradition for 20 years, created in honor of hockey mom Elfie Chapin who died from her breast cancer. Warm hearts in a VERY cold rink celebrated another successful tournament and made a presentation of $1963 to the Coalition.

LOCAL COMPANIES OFFERING A HAND

Fairport tech company Eagledream Technologies is dedicated to helping local companies transform and adapt to cloud technology business practices. They are also committed to supporting the Rochester community through charitable donations. We were pleased to receive a donation of $101 from their Super Bowl event. Thanks!

Kudos to local attorneys and staff at Boylan Code Attorneys at Law who raised a gift of $375 for us.

Our friends at Park West Women’s Health often run morale-boosting events in the office to raise donations for local groups. We are grateful for their recent gift of $135.66.

The Gates Fire District gave us a generous gift of $648 to support our programs and services.

Local restauranteur Ross Mueller owns a couple of Rochester’s hottest establishments, and is a generous giver within the community. Thanks, Ross, for a donation off $242 from October cocktail specials at Native and Label 7.

Farmington trucking company Leonard’s Express is continuing their long-running campaign of A Penny a Mile donation to the Breast Cancer Coalition from each of their four custom-painted pink rigs. This quarter’s road miles resulted in a donation of $885.80.

PINK POWERHOUSE

Her work starts within a couple of weeks of finishing her huge, thrilling, exhausting event; year after year, for nearly 20 years. Kathy O’Neill flashes her wide smile, and it would appear that few can say “no” when she asks for a basket, a gift card, a donation, tickets, autographs, small appliances, sports equipment. Every year, tables groan under the weight of rows and rows of tempting auction items; an equal bounty will be placed for those hardy souls who start their evening of bowling at 9 pm.

The teams who gather each year are clearly family, to each other and with Kathy. The sea of pink T shirts represents teams’ commitment to those they have loved and, in some cases, lost, to breast cancer. Survivors are applauded, friends remembered.

Kathy O’Neill’s Pink Bowl is more than a fundraising event (though it is an incredibly successful one!) It is a stunning example of one woman’s power to motivate and inspire the spirit of generosity and community that makes the annual Pink Bowl so successful.

Thank you Kathy and ALL who made this the largest, most fun, most successful Bowl ever. And THANK YOU for your donation of $19,000!
We are truly amazed at the many ways our generous donors support our work at the Coalition.

Some host fundraisers among their peers on social media or in person; others donate directly through their payroll with the help of an employer and/or the United Way. And there are those who respond to our annual fund campaigns, honor a loved one with an honorary or memorial gift, or simply return the donation envelope enclosed in this newsletter.

We are grateful to all donors for their valuable contributions and their commitment to our mission. Please join us in thanking the following individuals, companies, and organizations for their generous contributions between January 1 - March 31, 2020.

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Warriors, Survivors and Those Passed On
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Thank You, Donors!

LEADERSHIP OPPORTUNITY

The Breast Cancer Coalition is currently considering candidates for service on our Board of Directors. The Coalition is seeking volunteers for the July 2020 cohort interested in advancing the mission of the Coalition via a rewarding leadership opportunity. Service is for a term of two years. Details regarding expectations for directors and the desired qualifications for service can be found at www.breastcancercoalition.org/people. If interested, please contact Executive Director Holly Anderson at holly@bccr.org.

Thank you in advance for your interest in supporting the Breast Cancer Coalition.

IN KIND

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In our previous issue, we inadvertently misspelled the name of Shlonda Nash McKnight, whose 50th birthday was celebrated by a generous donation from Monika Katzol. We regret our error and wish Shlonda and Monika all the best!
Voices of the Ribbon is published quarterly by the Breast Cancer Coalition to provide encouragement and inspiration to those facing a breast and gynecologic cancer diagnoses, their supporters, and care providers.

In addition, it is intended to impart accurate, science-based information to enlighten and empower our readership.

Our in-house editor, graphic designer, writers, and support staff work together to ensure our publication is economically produced and our printers assure us that we are getting the best rates possible.

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E-Mail: info@BreastCancerCoalition.org
Online at www.BreastCancerCoalition.org

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Breast Cancer Coalition Inclusion Statement:
Just as cancer does not discriminate, the Breast Cancer Coalition recognizes the importance of a culture that strives for diversity. We appreciate individual differences whether color, race, religion, political viewpoints, socioeconomic status, physical abilities, gender, gender identity, gender expression, and/or sexual preference. We are committed to increasing the diversity within the Coalition and welcome you to our safe, inclusive community.

Tuesday, August 18, 2020
Ridgemont Country Club
• Staggered tee times beginning at 7am
• Tee times assigned in advance
• Curbside registration
• Box lunch & beverages provided
• Raffles & Online Silent Auction

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