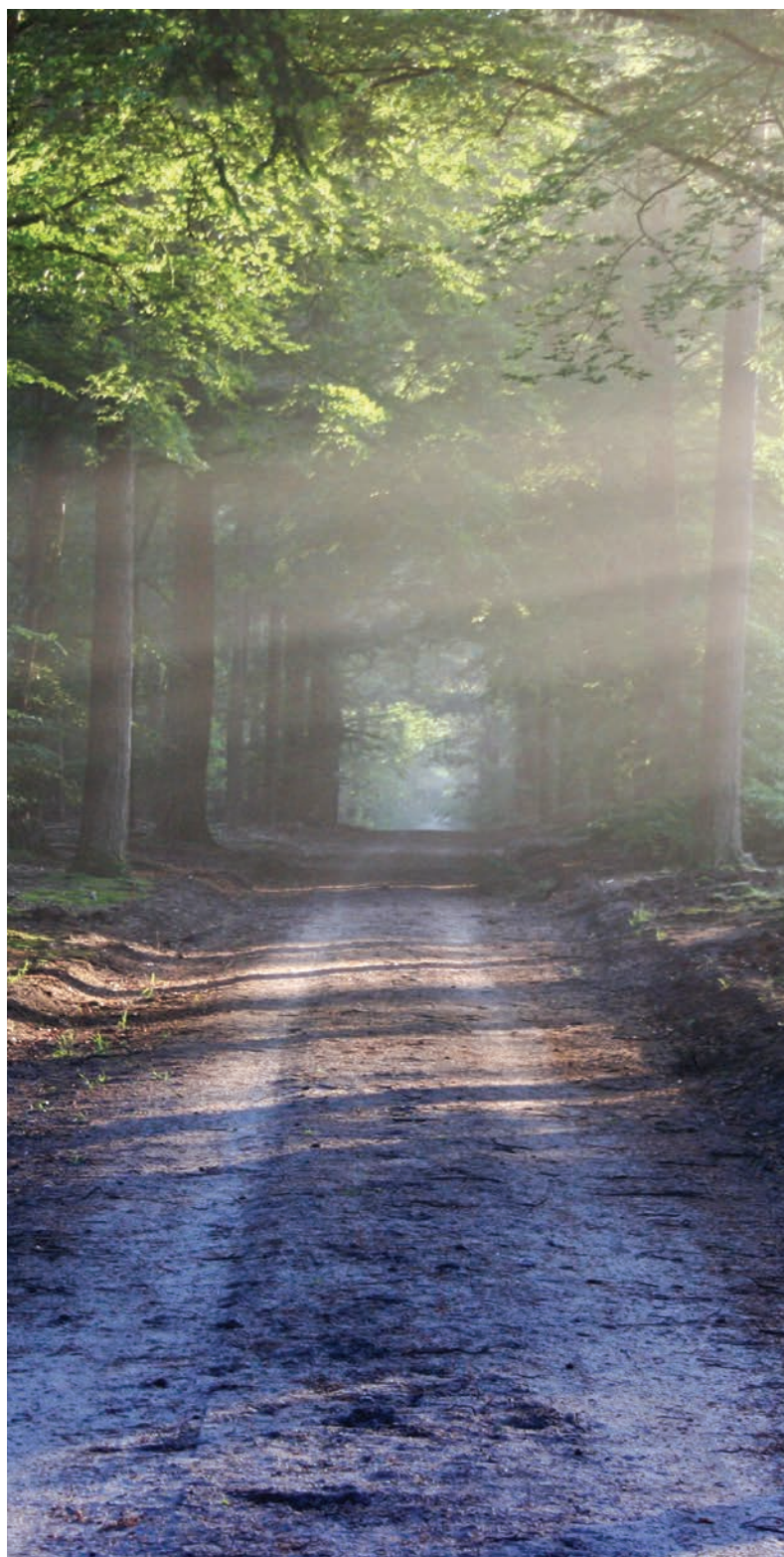


Connections Quarterly

SPRING 2018 ISSUE 65



Glens Falls Hospital
C.R. WOOD CANCER CENTER



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For more information about the Connections Quarterly newsletter or the C.R. Wood Cancer Center please call **518.926.6640**

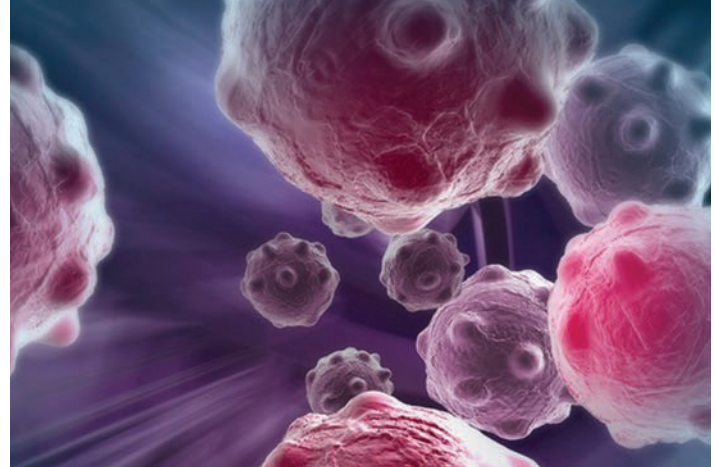
Research: The Best Medicine

By Aqeel A. Gillani, MD, FACP

Research is the holy grail of progress against cancer. In 2016, the White House announced the national Cancer Moonshot program and this has infused a renewed energy in cancer research. We have witnessed unprecedented advancements over the past couple of years. It is great news for our patients and a rewarding time to be an oncologist. Thanks to the exponential growth in the fields of immunotherapy, precision medicine as well as improvements in chemotherapy and radiation, patients are living better and longer. This would not have been possible without a willingness to participate in clinical research, collaboration between patients, the scientific community, federal agencies and the pharmaceutical industry.

The cancer death rate has decreased 23% since a peak in 1991. Two out of three people with cancer live at least 5 years after diagnosis. In the 1970s, only 50% of adults and 62% of children with cancer were surviving five years and today 68% of adults and 81% of children will be alive at least five years after a diagnosis. The number of cancer survivors has increased from 11.4 million in 2006 to 14.5 million in 2016. The FDA has approved a staggering 90 cancer drugs during this period of time.

While these trends are encouraging, we clearly face some major challenges and there are plenty of opportunities. We still lose about 600,000 lives to cancer each year in the United States. It is important to recognize that success in research relies on incremental gains and true breakthroughs are exceptional. While 50% of children are treated on pediatric cancer protocols, only 3-5% of adult patients with cancer participate in clinical trials. This is one reason that survival rates of adults with cancer remain inferior. Furthermore, it is difficult to accept that 95% of our standard practice relies on information gained from only 5% of patients in trials. A large majority of our patient population is frail and older and they have been grossly under-represented along with socioeconomically disadvantaged and ethnic minorities. It is estimated that 15 percent of U.S. cancer patients receive cancer care at an NCI designated center; the other 85% are diagnosed,



and receive at least their first course of treatment, at community hospital centers. The research innovators and leaders therefore look towards community-based centers like us to enroll patients into their trials.

A number of fundamental questions have been raised and it would require intense soul searching to find the answers. From a physician's perspective, how do we address the issue of clinical trial availability? Do we have the trials that ask the pertinent questions and do they fit our patient population? What steps do we take to disseminate this information to our patients and colleagues? What are some key barriers in terms of enrolling and retaining patients? How do we dispel misconceptions and myths? Are we willing to allocate resources and time that are required to engage in a frequently painstaking and labor-intensive process? And perhaps most importantly, what novel methods can we employ to find results that are meaningful to patient care in real-time?

We are standing at the footsteps of a major revolution in the field of oncology. It is incumbent upon us to maximize our potential and make sure that we are doing our best to encourage patient participation. At the same time, we need to ensure that our physician community is aware of cutting edge research, bring major national trials closer to our practice and become champions for our patients to understand and enroll in clinical studies. The medical oncology group at the C.R. Wood Cancer Center is highly committed to

bringing top quality research and clinical trials to our patients. We have a dedicated staff of six board certified hematologists/oncologists, three mid level providers, a research nurse and a certified research professional. A number of our patients have to travel to major tertiary care centers to participate in clinical trials and we see this area as a major unmet need for our community. Our team has taken several steps to fortify our research program this year. We have site-specific physician champions in all major areas of research including thoracic & head and neck cancers, breast oncology, gastrointestinal and genitourinary cancers, hematologic malignancies and non-malignant hematologic conditions. Having a physician leader in each of these areas will foster our ability to collaborate with our research partners at The University of Vermont in a more effective way. There has been a strong effort to expand this relationship. We have access to cooperative group trials including Alliance, NRG, SWOG and

I remain a strong believer that with resilience, focus and an unrelenting will to fight, we will overcome this “Emperor of All Maladies.”



ECOG. The U.S. pharmaceutical industry has made tremendous contributions to the field and we strive to bring exceptional new agents through our partnerships with them. Our patients are able to participate in Phase II & III treatment studies, prevention trials, diagnostic and quality of life studies. We are looking forward to building multidisciplinary teams and participating in site-specific tumor boards. This will most certainly enhance the patient experience and help to create a more enriched repertoire of clinical trials. I remain a strong believer that with resilience, focus and an unrelenting will to fight, we will overcome this “Emperor of All Maladies.”

CAR T Cell Therapies from cancer.org

Chimeric Antigen Receptor (CAR) T cell Therapy

Your immune system helps keep track of all the substances normally found in your body. Any new substance the immune system doesn't recognize raises an alarm, causing the immune system to attack it. CAR T cell therapy is a promising new way to get immune cells called T cells (a type of white blood cell) to fight cancer by changing them in the lab so they can find and destroy cancer cells. CAR T cell therapies are sometimes talked about as a type of gene or cell therapy, or an adoptive cell transfer therapy.

Cancer and the Immune System

To better understand how CAR T cell therapies work, it can help to know a little more about the immune system and cancer. Your immune system has many different kinds of cells that work together to destroy foreign substances. First, the immune system has to recognize that these substances do not belong in the body. It does this by finding proteins on the surface of those cells, called antigens. Some immune cells, like T cells, have their own proteins (called receptors) that attach to foreign antigens and help trigger other parts of the immune system to destroy the foreign substance. The relationship between antigens and immune receptors is like a lock and key. Just as every lock can only be opened with the right key, each foreign antigen has a unique immune receptor that is able to bind to it. Cancer cells also have antigens, but the immune system has a tougher time knowing cancer cells are foreign. If your immune cells do not have the right receptor (protein) to find a cancer cell's antigen, they cannot attach to it and help destroy the cancer cell.

The T cells used in CAR T cell therapies get changed in the lab to spot specific cancer cells by adding a man-made receptor (called a chimeric antigen receptor or CAR). This helps them better identify specific cancer cell antigens. Since different cancers have different antigens, each CAR is made for a specific cancer's antigen. For example, certain kinds of leukemia or lymphoma will have an antigen on the outside of the cancer cells called CD19. The CAR T cell therapies to

treat those cancers are made to connect to the CD-19 antigen and will not work for a cancer that does not have the CD19 antigen. The patient's own T cells are used to make the CAR T cells.

CAR T cell Therapy Steps

The process for CAR T cell therapy can take a few weeks. First, T cells are removed from the patient's blood using a procedure called leukapheresis. During this procedure, patients usually lie in bed or sit in a reclining chair. Two IV lines are needed because blood is removed through one IV, and then is returned to the body through the other. Sometimes a special type of IV line is used, called a central venous catheter, that has both IV lines built in. The patient needs to remain still for 2 to 3 hours during the procedure. During leukapheresis, sometimes calcium levels can drop and cause numbness and tingling or muscle spasms. This can be easily treated with calcium, which may be given by mouth or through an IV.

After the white cells are removed from the patient, the T cells are separated, sent to the lab, and genetically altered by adding the specific chimeric antigen receptor (CAR). This makes them CAR T cells. It can take a few weeks to finish making CAR T cells because a very large number of CAR T cells are needed for this therapy. Once there are enough CAR T cells, they will be given back to the patient to launch a precise attack against the cancer cells.

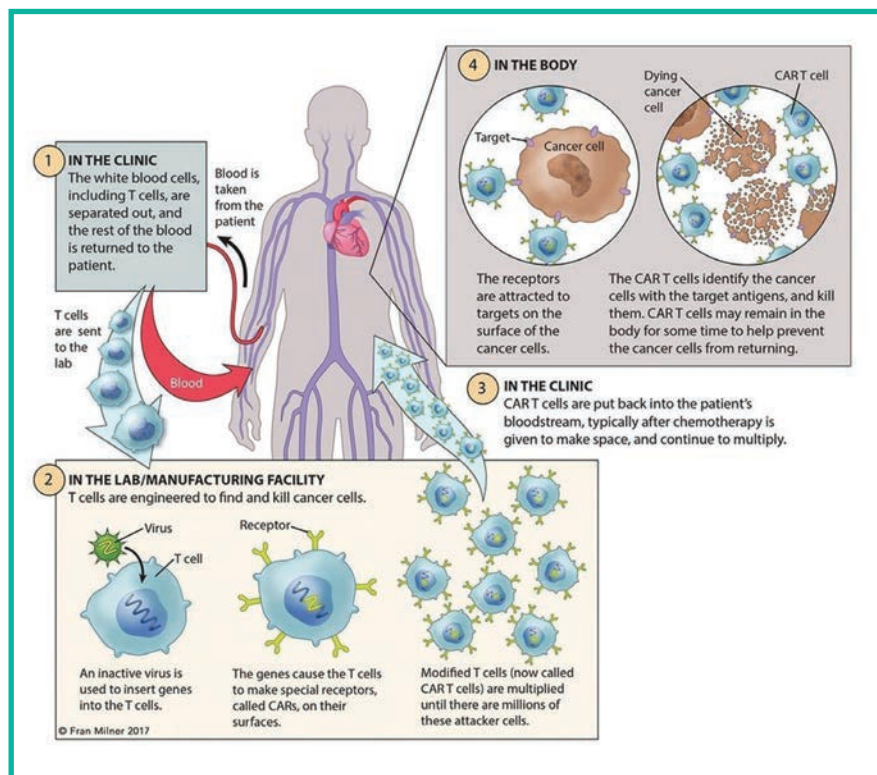
A few days before a CAR T cell infusion, a patient might receive chemotherapy to help lower the number of other immune cells so the CAR T cells have a better chance to get activated to fight the cancer. This chemotherapy is usually not very strong because CAR T cells work best when there are some cancer cells to attack. Once the CAR T cells start binding with cancer cells, they start to increase in number and can destroy even more cancer cells.

Approved CAR T Cell Therapies

Currently, there are two CAR T cell therapies approved for use in the United States. One is for advanced or recurrent acute lymphoblastic leukemia in children and young adults. The other is for certain types of advanced or recurrent large B-cell lymphoma. This type of lymphoma is one of several types of non-Hodgkin's lymphoma. This technique has shown very encouraging results in clinical trials against these cancers. In many patients the cancer could not be found after treatment, although it's not yet clear if these therapies will result in a long-term cure. In some patients the CAR T cells seem to go away after the cancer has been in remission for a while and researchers are studying whether those patients have a higher risk of their cancer coming back. Researchers are also studying long-term side effects of this kind of treatment. Other CAR T cell therapies to treat different types of cancer are being studied and are currently only available in clinical trials. For more information, see [What's New in Cancer Immunotherapy Research?](#)

CAR T-Cell Side Effects

Some people have had serious side effects from this treatment, especially as the CAR T cells multiply in the body to fight the cancer. Serious side effects can include very high fevers and dangerously low blood pressure in the days after it's given. This is called cytokine release syndrome, or CRS. Doctors are learning how to manage these side effects. Other serious side effects include neurotoxicity or changes in the brain that cause confusion, seizures, or severe headaches. Some patients have also developed serious infections, low blood cell counts and a weakened immune system. These side effects can be life threatening and it is important for patients to know what to watch for and to tell the cancer care team if any of these symptoms develop.



2,141 Days Since My Stem Cell Transplant and Counting

by Theresa Schaad

Mine is a story about getting your life back together after the treatment. I was diagnosed with Multiple Myeloma on October 25, 2011. I experienced chemo, stem cell transplant, isolation and recovery, and currently I am happy to say that I am cancer free. My team of doctors is from Memorial Sloan Kettering Hospital in NYC. I had chemo administered at my local hospital through Dyson Cancer Care Center in Poughkeepsie, NY.

I was lucky enough to be invited to Cindy's Retreat in September of 2012 – just five months after my transplant. I met other ladies that have gone through the rigors of balancing treatments, family, work and the big question - "Why Me?" The counselors there were a great source of information, they were compassionate,

and understanding. Throughout the weekend, we laughed, we cried, shared ideas and challenges. We made new friends. It was a weekend of re-birth.

Getting used to my new normal took a long time and to this day, I miss the activity level I used to have. I have come to terms with the "new me" and take care of everything I used to, but it just takes a little longer. Instead of a daily "to-do" list, I make a weekly list. And you know what? If it doesn't get done this week – tomorrow is another day. Listen to your body, if you need a nap – take one.

In my career before Multiple Myeloma, I was busy working as a photographer taking photos at weddings, schools, events and studio portraits. There are way too





Theresa Schaad

“Trust in your care team. They got you this far and they will get you through it”

many germs for someone that deals with an immune deficiency. I needed a new job. Instead, I now put my talent towards designing albums, retouching images and managing social media accounts for others. I have time to volunteer for our local photography group by acting as president and serve on the board of directors.

In the midst of recovery, I joined a book club with eight other women. We meet every five to six weeks. I'm reading books about topics I would have never thought to read, and learning so much.

As a way of giving back, I volunteer each year to raise money for LLS (Leukemia, Lymphoma Society) and offer to take photos of their walk. I also love to crochet. I, and three others, make child size afghans and donate them to the local Children's Hospitals where the little ones stay confined for weeks and sometimes months at a time. To date, we have delivered 86 afghans to local hospitals.

Feeling better is a chore. Eat right, get a good night's sleep, and listen to the doctors and above all take time for yourself. You've just been through hell and back. Go get the massage you wanted. Treat yourself to that restaurant that you thought was too expensive – go see that Broadway play. Who else deserves this? Did I mention vacation? We all know your life can change overnight. Go on a family vacation now, not next year. Creating memories is good for everyone.

Being diagnosed with the “C” word is a life changing event. Besides turning your world upside down, it can bring family and friends closer to you. Fortunately, you learn who your real friends are, and discover new ones. It's not easy for some to deal with your diagnosis. They are afraid, and unsure of what to say and do. Tell them! Come over for a cup of coffee and fill me in on what's happening in the neighborhood. You didn't change – you just hit a road block.

Try to enjoy life more, and stop worrying about the small stuff. Sure, there are days (mostly just before a doctor's appointment or test) that you start to feel vulnerable. It's normal. Trust in your care team. They got you this far and they will get you through it.

Most of all, each day that we are given is a bonus, make it count. Five years, ten months, nine days and counting.

Guide to Cruciferous Vegetables

By Andrea Chowske, RD, CD-N

What do kale, arugula and Brussels sprouts have in common? Aside from being the basis for trend-setting vegetable recipes, they're all delicious cruciferous vegetables and pack a nutritional and inflammation-fighting one-two punch.

Cruciferous veggies are a diverse group that includes broccoli, cauliflower, cabbage, kale, bok choy, arugula, Brussels sprouts, collards, watercress and radishes. Fun fact: The name "cruciferous" is an informal classification for members of the mustard family and comes from the Latin *cruciferae* meaning "cross bearing," because the four petals resemble a cross.

While these veggies grow in all different colors, shapes and sizes, they share several nutritional benefits. Most cruciferous veggies are rich in vitamins and minerals such as folate and vitamin K. Dark green cruciferous veggies are also an excellent source of vitamins A and C. They're also rich in phytonutrients — plant-based compounds that may help to lower inflammation and reduce the risk of developing cancer. Cruciferous vegetables also are rich in fiber and low in calories, a combination that will help you feel full and satisfied without overeating.

It doesn't take much to reap the benefits. Adults need at least 2½ cups of vegetables a day. One cup of raw and cooked veggies, such as broccoli, cauliflower and Brussels sprouts, is equivalent to a 1-cup vegetable serving. Two cups of raw leafy vegetables, such as kale and bok choy, are the equivalent of a 1-cup vegetable serving.

Ready to add more cruciferous veggies into your diet? These tips will make packing in your vitamins and minerals easy and enjoyable.

Cauliflower

This versatile veggie is delicious in many ways beyond steaming. Try roasting florets or "steaks" of cauliflower to release its pleasant flavor. When pureed, it's a great substitute to cream sauce. Other creative cauliflower options? Mash into a pizza crust, grate into a substitute for rice or pickle for a low-calorie salty, crunchy snack.

Brussels Sprouts

Brussels sprouts practically beg to be in the oven. For a melt-in-your-mouth side, roast and toss with something sweet, such as dried fruit or maple syrup, as well as something savory — anything from Parmesan cheese to sliced olives.

Kale

The almighty kale is a wonderful green for salads. Remove the tough stem, slice into thin ribbons and toss with toppings, dressing and all. Best of all, this hearty green will not wilt for days, making it a great option for packing ahead. To balance the bitter bite, pair it with something sweet such as roasted carrots, diced apple or dried fruit. Kale also is a great addition to smoothies and can even be baked into crisp chips.

Arugula

Arugula is one of the easiest greens to grow in your garden or in a planter. Enjoy this spicy leaf pureed into a pesto with a kick, tossed onto whole-wheat pizza once it emerges from the oven or used in a variety of tossed salads. For a classic combination try fresh arugula paired with feta cheese, cubed watermelon and a balsamic dressing.

Article from www.Eatright.org



For general questions about cancer or support services available, please call: Nurse Navigators: Vickie, at 518.926.6639, Lisa, at 518.926.6563 or Nicole, at 518.926.6629

Services for Individuals By Appointment

Care Management

For: Continuing care needs, transportation and financial concerns
Info: Karen Cook, LMSW | 518.926.6619

Chemotherapy Education Class

For: Individuals & family starting chemotherapy
Meets: Tuesdays at 4:00pm in the Cancer Center Library or by appointment at your convenience
Info: Vickie Yattaw, RN, BSN, OCN® | 518.926.6639
Lisa Haase, RN, BSN, OCN® | 518.926.6563
Nicole Molinero, RN, OCN® | 518.926.6629

Clinical Research

For: Anyone interested in learning about clinical trials
Info: Beth Brundage, RN, OCN® | 518.926.6644

Genetics Counseling

For: Anyone concerned about their personal or family history of cancer
Info: Rebecca Kerr, MSc, CGC | 518.926.6574

Nutrition Counseling

For: Anyone interested in dietary counseling
Info: Andrea Chowske, RD, CD-N | 518.926.2635

Pastoral Care

For: Anyone interested in spiritual counseling
Info: 518.926.3531

Patient Financial Assistance

For: Referrals, prior authorizations, billing, insurance questions
Info: 518.926.6639

Psychosocial Oncology

For: Counseling for patients and/or their families
Info: Gerry Florio, Ph.D.
Call: 518.926.6640 for an appointment

Nurse Navigators

For: Individuals & family diagnosed with any cancer
Meets: By appointment or stop by
Info: Vickie Yattaw, RN, BSN, OCN® | 518.926.6639
Lisa Haase, RN, BSN, OCN® | 518.926.6563
Nicole Molinero RN, OCN® | 518.926.6629

Spa Services at Cindy's Healing Place

Massage Therapy

For: Cancer patients during and after treatment
Meets: By appointment at Cindy's Healing Place
Info: 518.926.6640

Uniquely You® Boutique & Salon

For: Any cancer patient
Free wigs, hats & turbans, skin & hair care
Meets: By appointment on Tuesdays in the C. R. Wood Cancer Center
Info: 518.926.6640

Special Programs

Pre-Registration Required

CG Men's Retreat

For: Men living with and beyond cancer
Meets: One weekend each year in the Fall
Info: Vickie Yattaw, RN, BSN, OCN® | 518.926.6639

Cindy's Comfort Camp

For: Children and teens ages 6-17 years who have experienced the death or serious illness of a parent or close relative
Meets: One weekend each Spring and Fall at the Double "H" Hole in the Woods Ranch in Lake Luzerne
Info: 518.926.6640

Cindy's Retreat

For: Women living with and beyond cancer
Meets: One weekend each Spring and Fall at Silver Bay on Lake George
Info: Karen Cook, LMSW | 518.926.6619

Breast Cancer Survivors Luncheon

For: Breast Cancer Survivors and a guest
Meets: One Saturday in October
Info: Lisa Haase, RN, OCN® | 518.926.6563

Survivor Breakfast

For: Any cancer survivor and a guest
Meets: One Saturday in June
Info: Vickie Yattaw, RN, OCN® | 518.926.6639

Summer Picnic

For: Any cancer survivor and their family
Meets: One Wednesday in August
Info: Vickie Yattaw, RN, OCN® | 518.926.6639

Holiday Party

For: Any cancer survivor and their family
Meets: One Wednesday in December
Info: Lisa Haase, RN, OCN® | 518.926.6563

These groups are open-ended and you may come as you wish. You may want to call if you are new or you have not come for some time to make sure that the schedule or location has not changed.

Discussion Groups

ABC Support Group *After Breast Cancer*

For: Individuals with breast cancer
 Meets: 4th Monday each month
 6:00pm | Cancer Center Waiting Room
 Info: Lisa Haase, RN, BSN, OCN® | 518.926.6563

Blood Cancer Support Group

For: Individuals & family diagnosed with lymphoma, leukemia or multiple myeloma
 Meets: 2nd Wednesday each month
 6:00pm | Community Learning Center, Side A
 Info: Karen Cook, LMSW | 518.926.6619

Prostate Cancer Awareness Group

For: Men with prostate cancer and their families
 Meets: 3rd Thursday each month
 7:00pm | Cancer Center Library
 Info: Vickie Yattaw, RN, BSN, OCN® | 518.926.6639

Rays of Hope

For: Women with ovarian cancer
 Meets: 3rd Wednesday each month
 4:00pm | Cancer Center Library
 Info: Mary Davis | 518.656.9321
 Carol Smith | 518.793.0565

Round Table Support Group

For: Individuals with any cancer and their families
 Meets: 1st Wednesday each month
 4:00pm | Cancer Center Library
 Info: Karen Cook, LMSW | 518.926.6619

Tobacco Cessation

Info: Whether you're thinking about quitting or ready to quit, call the NYS Smokers' Quit Line for help and support
 1.866.NY.QUITS | 1.866.697.8487

Activity Groups

Healthy Steps®

For: Gentle exercise for individuals with a cancer diagnosis
 Meets: Tuesdays at 10:00am | Community Learning Center (Side B)
 Info: Vickie Yattaw, RN, BSN, OCN® | 518.926.6639

Tai Chi and Relaxation/Meditation

For: Anyone interested
 Meets: Monday afternoon at 3:30pm and 5:30pm
 Community Learning Center (Side B)
 Info: 518.926.1000

Twisted Twirlers

For: Individuals diagnosed with any cancer and caregivers who would like to join this Hall of Fame twirling group. New twirlers are always welcome!
 Meets: 11:30am | 1st and 3rd Tuesday each month
 Community Learning Center (Side B)
 Info: Barbara Ringer | 518.792.7437

Ways of Seeing - Arts and Crafts Workshop

For: Individuals & family diagnosed with any cancer who want to enjoy the life affirming pleasures of creating art
 Meets: 2nd and 4th Tuesday each month at 11:30am
 Cancer Center Library
 Info: Vickie Yattaw, RN, BSN, OCN® | 518.926.6639

Quit for Life *Stop Smoking Program*

A four-week program for anyone who would like to quit smoking. Please note: pre-registration is required.

April 10th - May 1st, 2018,
 Tuesday nights from 6:00pm - 7:00pm
 in the C.R. Wood Cancer Center Library.

For information or to register, please call Lisa Haase, RN, BSN, OCN® at **518.926.6563**.

Hematologic Malignancies Being Studied

By Your Clinical Research Team

Clinical research is vital to the process of discovering the safest and most effective cancer therapies for patients. The C. R. Wood Cancer Center (CRWCC) participates in national clinical trials. These studies provide the opportunity for patients to conveniently receive some of the most cutting edge therapies available, while also allowing them to directly contribute to the ongoing progress being made in the field of Oncology.

Study 1

Study Title: Connect® MDS and AML: The Myelodysplastic Syndromes (MDS) and Acute Myeloid Leukemia (AML)

Sponsor: Celgene Corporation

Description: This study is called an observational study. An observational disease registry study means that only information about your disease and medical treatment that your study doctor is already prescribing as part of your standard medical care is collected. Standard medical care is the treatment normally given for a certain condition or illness.

You will continue with your standard medical care and continue with any medicines you are now taking, office visits and laboratory testing according to the normal routine practices of your CRWCC physician. No additional medication, or payment for medication, is provided as part of this study. There is no investigational drug involved in this study. There will be no additional study visits, procedures, or testing required to be in the study. A blood specimen is drawn at the start of the study and this will be done during a scheduled visit. It will be drawn only once. We will only collect this information as it relates to the standard medical care you are receiving.

This study will observe and collect data for people with one of the three following diseases:

Myelodysplastic Syndrome (MDS)

MDS is a disease where a person with the disease has low blood cell counts and bone marrow failure. Bone marrow failure is when your bone marrow is not

making enough properly developed white blood cells, red blood cells or platelets.

Idiopathic Cytopenia of Undetermined Significance (ICUS)

ICUS is a condition where a person has unexplained, persistent (for equal to or more than six months) changes in number of certain cells in the blood (red blood cells, white blood cells, platelets and granulocytes). If you have ICUS a diagnosis of Myelodysplastic Syndrome (MDS) cannot be made for certain. Persons with ICUS are at increased risk of developing MDS and AML (see above and below).

Acute Myeloid Leukemia (AML)

AML is a type of cancer in which the bone marrow makes abnormal myeloblasts (a type of white blood cell), red blood cells, or platelets. People with two different types of MDS and people with ICUS or AML will be included in this study.

If you have MDS, your study doctor will assign you to one of the two different groups below:

Lower-Risk (LR) group Higher-Risk (HR) group

Severe forms of MDS are usually defined as having a low red blood cell count that does not respond to treatment; and having too many blasts in the bone marrow. These forms of MDS may develop into Acute Myeloid Leukemia (AML). If you have ICUS, it means that you can have a low red blood cell count, a low white blood count or a low platelet count. ICUS may also develop into MDS or AML. There is a need for further information in routine medical practice to document the outcome of these diseases. Assigning

participants in this study to risk groups, like Lower-Risk or Higher-Risk, to help predict disease outcomes, and treatment patterns of people like you, who have been diagnosed with either MDS or ICUS or AML will assist with this goal.

About 1,500 participants in the U.S. will be in this study. This includes about 700 people with Lower Risk (LR) MDS, about 200 people with Higher Risk (HR) MDS, about 200 people with ICUS, and about 400 people with AML.

The amount of time you will be followed in this study will be eight years. You will be asked to complete Quality of Life questionnaires every three months for the first year then every six months for the remaining time. These are brief and typically take 10-15 minutes to complete. If you are not scheduled to see your Medical Oncologist when the questionnaire is due, it may be mailed to you or a member of the research team will call you and complete this over the phone with you.

Being in this study does not replace your standard medical care. Being in this study should have no impact on whether you would be able to participate in another clinical trial. The oncologist currently treating you will assist you in determining if this registry may be right for you.

If you think that you may be eligible and would like to learn more about this registry, please contact our research office at:

518.926.6644 or **518.926.6701**

Study 2

Study Title: E1A11 Randomized Phase III Trial of Bortezomib, LENalidomide and Dexamethasone (VRd) Versus Carfilzomib, Lenalidomide and Dexamethasone (CRd) Followed by Limited or Indefinite DURATION Lenalidomide MaintENANCE in Patients with Newly Diagnosed Symptomatic Multiple Myeloma (ENDURANCE)

Sponsor: ECOG-ACRIN

Description: This study may be available to you if you

are diagnosed with multiple myeloma that requires treatment. The treatment combinations that are being compared in this study are both effective, but they have different side effects, which can impact whether patients tolerate the treatment for a prolonged time. This study has two parts, the first is related to the initial treatment of your myeloma (also known as induction) and a second part is related to continued long term control of the myeloma (also known as maintenance). The purpose of the first part of the study is to compare the effects, good and/or bad, of one combination of the drugs versus the other combination. The second part of the study will examine if it is better to continue lenalidomide until the myeloma comes back or limit it for a defined period of two years.

This is a treatment study. You will be randomized to one of two treatment groups for the first step. Depending on the medications you are to receive, some of the study drugs may be provided by the study group and others will be commercially available and a prior authorization will be sought through your insurance company.

About 750 people will take part in this study. To be eligible to participate in this study, you must not have received prior treatment for your myeloma except for a short (four weeks or less) period of treatment. Patients on all arms of this trial will be asked to complete a 30-minute questionnaire to assess wellbeing during and after the study. This is known as Quality of Life. The oncologist currently treating you will assist you in determining if this study may be right for you.

For more information, please contact our research office at

518.926.6644 or **518.926.6701**

References:

NCCN guidelines version 2.2017

www.cancer.gov (NIH cancer causes and prevention)

www.uptodate.com (Nov 14, 2017) McQuillan G, Kruszon-Moran D, Markowitz LE, et al. Prevalence of HPV in Adults Aged 18–69: United States, 2011–2014. NCHS Data Brief, No 280. Hyattsville, MD: National Center for Health

Precision Medicine

By Darci Gaiotti-Grubbs, MD
Medical Oncologists, C.R. Wood Cancer Center

The management of cancer continues to evolve. For many years, the predominant systemic therapy option for early and advanced-stage malignancies has been chemotherapy. Chemotherapy works by disrupting cell division and thereby the growth and propagation of cancer cells. However, the mechanisms by which chemotherapy kills cancer cells are not selective for cancer cells and as a result there is collateral damage to a patient's healthier cells, with resultant significant toxicities, such as loss of hair, mouth sores, diarrhea, low blood counts, etc.

In recent years, there has been a paradigm shift in the approach to treating cancer, often referred to as "precision oncology" or "personalized cancer care." With this approach, treatment decisions are customized to the specific genomic profile of a cancer, rather than only the more traditional properties of the cancer, such as primary site, stage, etc. Every cancer is thought to be genetically unique. Genomic profiling of a tumor refers to using various laboratory methods to delineate the important genetic alterations/gene mutations of that tumor that are in fact driving its growth and survival. With this information in hand, more novel therapies specifically targeting these mutations can then be invoked for treatment of a patient's cancer. Not only are these targeted therapies often more effective than chemotherapy, but they are often also less toxic because their mechanism of action is more selective for the cancer cells. In addition, they can also be used in combination with chemotherapy to improve response rates. This represents a much more "personalized" approach to treating patients.

Currently, genomic profiling of tumors is being used mostly in the metastatic setting, sometimes to guide first-line therapy but more often after patients have failed more standard therapies due to intolerance or progression of disease. For the last several years, genomic profiling on a limited level has been used routinely in certain cancer types, such as lung cancer. For example, patients with non-small cell lung cancer with an activating EGFR mutation are candidates for such drugs as Tarceva. Much more expansive gene panels have now become available for profiling



of common and rare tumor types. One example of an FDA-approved commercially available genomic profiling test is Foundation One CDx. The FoundationOne CDx test assesses genomic alterations in 324 genes known to drive cancer growth. FoundationOne CDx also reports genomic biomarkers, such as micro-satellite instability (MSI), and this information can guide oncology providers regarding other treatment options, such as immunotherapies and relevant clinical trials. Another recently FDA-approved genomic profiling test is the MSK-IMPACT, which is a 468-gene panel. Of note, genomic profiling is typically performed on a tissue sample of your tumor but can also sometimes be performed on a blood sample. At the C.R. Wood Cancer Center, we are primarily using the Foundation One CDx assay to do genomic profiling for patients where we feel it is appropriate. The Guardant 360 assay is also available. We are actively tracking how the use of this information is impacting our patients' access to therapies that might not have been considered otherwise. We encourage you to speak to your oncologist to see if such testing is appropriate for you. It is important to understand that the genetic makeup of a tumor is dynamic rather than static; as such, your provider may recommend a fresh biopsy to ensure that the testing reflects the current status of your cancer.

The approach to cancer care continues to evolve and we at the C. R. Wood Cancer Center continue to work hard to keep pace with these changes and advancements for the benefit of our patients.

References:

Cancer Medicine 2017; 6(1):195–206 , NCI/NIH website: <https://www.cancer.gov>, <http://www.businesswire.com/news/home/20171130006320/en/and> [foundationmedicine.com](http://www.foundationmedicine.com), MSKCC.org>pressroom>press releases.

Why Did This Have to Happen to My Family?

By Katie Bain

My first time going to Camp in 2009, I wasn't sure how to feel. I was ten years old, and my mother had been diagnosed with Primary Progressive Multiple Sclerosis (PPMS) around seven years prior. Although her illness was something very relevant throughout my lifetime, as a kid, I never thought too much about how to deal with it. School got more difficult as I got older, as other kids would ask me why my mom was in a wheelchair, or why she couldn't talk. I never knew what to say, as I hardly knew what was going on myself. I felt different in comparison to my friends and classmates, and I hated how uncomfortable talking about my parents made every situation. I felt very alone and segregated from other kids. Why did this have to happen to my family?

Although I was very hesitant walking into an environment and spending an entire weekend with complete strangers, I did not realize that this experience would give me relationships that would last a lifetime. The advice and strategies that I attained from the counselors in the group therapy sessions truly changed my outlook on life, and influenced the way I cope with my emotions to this day. Additionally, for the first time in essentially my entire life, I realized that I was not "different." I could finally understand that there are other kids out there, going through a very similar situation as me. I was not only able to share my story, emotions, and coping strategies with kids my age, but I was also able to listen to and learn from others' experiences. I finally recognized that I was not alone, and that expressing my emotions was okay. I learned to deal with my feelings of stress, anger, and even sadness, while having fun and enjoying myself as a kid at the same time.

It was this sense of community and family that I found in Cindy's Comfort Camp that has made it irresistible for me, and many others, to come back as a volunteer. This camp made me a much stronger person, and gave me a sense of belonging that I never thought I would have. I can't put into words how grateful I am to have been able to participate in this experience, both as a camper and a volunteer.



Katie (on the left) as a camper with fellow camper, Martha in 2009



Katie (on the right) as a Big Buddy volunteer with Little Buddy, Tessa in 2017

Volunteer Opportunities Available

Cindy's Comfort Camp relies heavily on volunteers to make this camp run.

Volunteers come in the form of healing circle leaders, big buddies, cabin leaders, and arts & crafts leaders.

For more information on open Volunteer possibilities please call Suzy Virgil at **518.926.6640** or email svirgil@glenfallshosp.org

Cindy's Comfort Camp



Cindy's Comfort Camp is a special weekend camp for children & teens touched by the serious illness of a parent or sibling.

This free, weekend overnight camp is located at the Double H Hole in the Woods Ranch in Lake Luzerne and is for children and teens ages 6–17.

Over the course of the weekend, the campers share their experiences, help each other cope, and enjoy time away from the stressors of their day life.

The next camp is scheduled for May 18–23, 2018. The camp is limited to 30 campers. For more information, contact us by:

Phone: **518.926.6640**

Email: **svirgil@glensfallshosp.org**

Web:
glensfallshospital.org/services/community-service/cindys-comfort-camp

Facebook:
www.facebook.com/pg/GlensFallsHospital/events/?ref=page_internal

A Place for Fun

Having fun is a part of every kids job description. That's why fun is such an important part of Cindy's Comfort Camp. Our campers enjoy a weekend filled with games, sports, hiking, boating and arts and crafts; all at the beautiful Double H Hole in the Woods Ranch in Lake Luzerne.

A Place for Sharing

Our "Healing Circle" group sessions provide campers with the opportunity to explore and express their thoughts and feelings with their peers and our professional grief counselors. Counselors are also available to talk one-on-one with the campers. At the conclusion of camp, families are invited to rejoin us for a special celebration of hope and caring.

A Place for Connecting

In addition to the friendships that quickly form between campers, each participant at Cindy's Comfort Camp is matched one-to-one with a trained adult volunteer, known as a "Big Buddy". Big Buddy serves as the campers mentor and friend for the weekend, joining them in activities, providing a listening ear and a comforting smile and all the encouragement a camper may need.





Free Skin Cancer Screening

Saturday, April 14th, 2018
9am-12pm

C.R. Wood Cancer Center
 Glens Falls Hospital
 100 Park Street

Appointments required
 Please call **518.926.6640**



Cindy's Retreat

April 27-29th, 2018 at the Silver Bay
 YMCA Resort and Conference Center

For any woman at any time after a diagnosis of cancer. A great weekend away to connect with others, relax, unwind and refresh. For more information please call Karen Cook, LMSW at **518.926.6619**.

We cordially invite you and your guests to join us for breakfast at

The Ninth Annual Spring Survivorship Celebration

Saturday, June 2nd, 2018

Registration: **8:30-9:00am**
 Buffet Breakfast: **8:30am**
 Program: **10:00am**
 RSVP required

The Gideon Putnam Resort
 24 Gideon Putnam Road
 Saratoga Springs, New York

For more information Contact Lisa Haase, RN, BSN OCN© **518.926.6563**



Cindy's Comfort Camp

A special weekend for children & teens living with a parent or sibling with a serious illness. This is a free, weekend overnight camp, located at the Double H Hole in the Woods Ranch in Lake Luzerne, for children and teens ages 6-17. Next camp will be scheduled for **May 18th-23rd, 2018**. For more information contact us at: **518.926.6640**.

Clinical Research at the C.R. Wood Cancer Center at Glens Falls Hospital

If you have been diagnosed with cancer, you may want to talk to your physician about taking part in a clinical trial. Clinical trials may offer treatment options for patients with cancer that are not otherwise available.

- If you have just found out that you have cancer, the time to think about a clinical trial is before you make a treatment decision. Talk with your doctor about all your options, including a clinical trial.
- Other clinical trials are looking for people who have already been treated for their cancer.
- If you have already had one or more forms of cancer treatment and are looking for a new treatment option, there may still be a clinical trial for you to think about.

Please call our research office at **518.926.6644** or **518.926.6701** for more information about clinical trials available at Glens Falls Hospital or visit our website at:

www.glensfallshospital.org/CRWood-Cancer-Center/clinical-research/clinical-research.cfm

You may also want to visit the National Cancer Institute website for other clinical trials at

www.cancer.gov/clinicaltrials

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C.R. Wood Cancer Center, Glens Falls Hospital,
Glens Falls, NY 12801

E-mail: svirgil@glensfallshosp.org

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Cancer Services Program (CSP)

Men and women who are uninsured, meet eligibility criteria and are in need of treatment for breast, cervical, colorectal or prostate cancer screening, may be eligible for full Medicaid coverage through the Medicaid Cancer Treatment Program. Coverage is arranged through the Cancer Services Program Case Manager and will last for the entire treatment period.

Glens Falls Hospital provides a New York State Department of Health Cancer Services Program grant that funds breast, cervical and colorectal cancer screenings and follow-up testing at no cost for uninsured women and men. If you or someone you love is without health insurance, call today at:

1.800.882.0121 or **518.926.6570**



When and How to Make the Call

518.926.6620

Medical Oncology

When you call during clinic hours (**8:30am to 4:30pm weekdays**), you will reach the telephone triage nurse. Her phone number is **518.926.6620**, the number you are given to call if you have any questions or problems.

If it is an emergency, please call 911.

When you call you will very likely need to leave a message as she is often busy with other patients who have also called. Please try to speak clearly (without rushing) giving the following information in the message to help her assist you efficiently:

- Your name, or the name of the person you are calling about (please spell the last name)
- Date of birth
- Your doctor's name (not the PA because they work with multiple doctors)
- Your phone number (or where she can best get back to you)
- The reason why you are calling

If you are calling for a medication refill, please also include:

- The name and location of the pharmacy you use
- The medication and the dose



You will need to allow 48 hours to have the medications refilled. Most prescriptions will be sent to your pharmacy by e-mail (e-scribed). If it is a medication that cannot be sent electronically, we will call you back with instructions.

If you are having a medical problem, we will try to call you back within two hours. Please be patient as sometimes many calls come in within a short period of time.

My Health Record | <https://glensfalls.iqhealth.com>

Allow 48 hours for a response. If you are having a medical problem that needs prompt attention, it is better to call us and leave a message. My Health Record is designed to provide a brief summary of your most recent visit with your doctor. Unfortunately, it is not an efficient forum for a detailed discussion with your care team. It is better to call with questions or, if appropriate, wait to discuss them at your next visit.

Many doctors return their calls (especially test and lab results) at the end of their clinic or at lunch time, so it may be a few hours before they get back to you. When you call, you can let us know if it is okay for them to leave a message with the results on your answering machine.

If you call after hours and need a response, (evenings, nights, or weekends) please tell the answering service to page the on-call doctor. No one is available to check messages during off hours so it will not be received until the next business day.

Radiation Oncology

Patients receiving radiation therapy who have questions during clinic hours (**8:00am to 4:00pm weekdays**) should call the Radiation Therapy Department at **518.926.6670** and ask to speak to a nurse. You will be directed to Kelle Engel RN, BSN, OCN or Kit Howard, RN, OCN. If they are not available to speak with you, please leave a brief message with a call back number. You should expect a call back within 20 to 30 minutes.

If it is an emergency, please call 911.

If you have questions or concerns after the department closes or on the weekend, please call the same number, **518.926.6670**. An answering service will take your information along with a phone number and a radiation oncologist will return your call. Please do not wait with a problem. The radiation oncologists are on call to address any of your concerns.