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H.O.P.E.'s Office Hours are Monday through Friday, 9:30—3.

<u>Please call in advance</u> to set up an appointment for:

- Intake
- Wigs/hats/scarves
- Pantry

Please direct all calls to the H.O.P.E. office at **717-244-2174**.

## **Support Group**

Date: Wednesday, July 10

Time: 7:00 p.m.

Location: H.O.P.E. Haven

Topic: Everything

# H.O.P.E. LIFELINE



H.O.P.E. (Help for Oncology Problems & Emotional Support) is an all volunteer cancer support network that provides free assistance to cancer patients and their families facing the challenges of cancer. H.O.P.E. is a 501 (C)(3) non-profit funded through donations. Our office is located at 13275 Blymire Hollow Road, Stewartstown, PA. The official registration and financial information of Help for Oncology Problems and Emotional Support may be obtained from the Pennsylvania Department of State by calling toll free, within Pennsylvania, 1 (800) 732-0999. Registration does not imply endorsement.

H.O.P.E. does not receive funding and is not affiliated with the American Cancer Society. Funding comes from donations made by private individuals and the civic/business community.

Phone: 717-244-2174 or 717-244-2161.

(E-mail: barb@hopeforcancerfamilies.org www.hopeforcancerfamilies.org)

## Gift Card and Raffle Tickets!

Battlefield HOG Chapter #4330 50/50 Raffle Ticket—\$5.00 Drawing Sunday, July 14, 2024 Do not have to be present to win. (www.forelifeline.org or 717-244-2174)

Where's the Beef? \$500 Gift Card for Omaha Steaks Tickets are \$5.00 or 3 for \$10.00

Drawing held at the Shrimp and Bull Roast, October 5th, at the Jarrettsville Gardens, MD.

Call the office 717-244-2174



## Take a Swing at Cancer!

16th Annual Golf Classic Tournament

Saturday, August 17
Hickory Heights Golf
Course

Spring Grove, PA

Continental Breakfast, Lunch, Lots of Prizes

Hole-In-One on #17 Wins \$5,000 for you/\$5,000 for H.O.P.E.

Call 717-244-2174 for information.

# H.O.P.E.'S CURRENT ADDRESS

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## FROM THE EDITOR'S DESK

Happy Fourth of July. Summer seems to be the time we celebrate our country and its founders and the brave men and women who dedicated so much to creating and preserving our democracy, often at the cost of their lives. First is Memorial Day, to honor our veterans of the world wars; then a couple weeks later is Flag Day, to honor our flag that represents the pride we have for our country and citizens; and then the Fourth, the day on which was passed the Declaration of Independence, announcing our separation from Great Britain. It's a grand old flag indeed.

Let's hope the flag can continue to fly long and proud as our planet reels from the consequences of a changing climate. A heat index of one hundred and three degrees in Maine in June is just one example. Record-high temperatures and heat waves are occurring all over the U.S., accompanied by unprecedented numbers of wildfires, tornadoes, and hurricanes. Science fiction is becoming reality.

It's a tough time for almost everyone, particularly those who are hit with unexpected setbacks like a cancer diagnosis. Our newsletter hopes to remind you that Barb and Carol and everyone in the office are here to provide a variety of assistance and support, as well as a physical getaway in the country at Hope Haven. Call the office at 717-244-2174 to find out how to sign up for a stay at the Haven, as well as any other questions you may have concerning our food pantry and all the other ways we assist our patients and their families.

Speaking of assisting our patients, in this issue we have information about health insurance and a detailed explanation of clinical trials—what they are and whether you should consider one. We also have our annual reminder of the importance of using sunscreen and have researched the most recommended brands for use on faces. Now more than ever we need to cover up when outside these days, even when it's cloudy.

July is National Sarcoma and Bone Cancer month. A sarcoma is a rare kind of cancer. Sarcomas grow in connective tissue—cells that connect or support other kinds of tissue in your body. These tumors are most common in the bones, muscles, tendons, cartilage, nerves, fat, and blood vessels of your arms and legs. There are two main forms: soft tissue sarcoma and bone sarcoma, or osteosarcoma. They can be treated, often by having surgery to remove the tumor. It's important to realize that children and young adults get this second type of sarcoma more often than adults, and because healthy, active children and teens often have pain and swelling in their arms and legs, osteosarcoma might be mistaken for growing pains or a sports injury. If the child's pain doesn't get better, or gets worse at night, it's advisable to talk to a doctor. Adults who have this kind of pain should see a doctor right away.

Barb would like to thank all those who shopped at Saubel's and collected and donated stamps. Who knew such tiny things could earn so much for HOPE! The pans we received will be wonderful Christmas gifts for our patients and their families. Now that you've gotten into the habit, we hope you'll keep collecting so that we can continue to share your largesse.

## H.O.P.E.'S ANGEL CORNER BY BARB TITANISH, PRESIDENT & CO-FOUNDER H.O.P.E.

Over 15 years ago the Mid-Atlantic Women's Motorcycle Rally group adopted HOPE as one of their charities. Every year I go to this 3-day event wherever it is being held, this year it was held in Gettysburg. I love this group for two main reasons, first, they are such a giving group of ladies. I have made so many friends there over the years and every year more attend. This year they had more than 350 women bikers from all over the East Coast in attendance. Second, this is where I met Carol, my assistant, and 7 years ago she joined us at HOPE. She is my right-hand gal and she makes the office run so smoothly. Carol had been on the MAWMR Board for 25 years and was one of the original members. She is one of four who have attended every Rally over the past 34 years. We do not have a number made from this event yet but even in this heat, it was a successful event. So, I just wanted to let my friends at MAWMR know how thankful we are for them and how lucky I am to call them my friends. I also, have to thank them for sending Carol my way because she is my right-hand gal!



"When gardeners garden, it is not just plants they grow, but the gardeners themselves."

~ Ken Druse

If you would prefer to receive our newsletter by email (and help us save postage), please send a note to our Assistant Director Carol Nelson, at assistant@hopeforcancerfamilies.org, and she'll put you on our list. (And it will have color!) Thanks!

## A Primer on Clinical Trials and Their Pros and Cons

A recent study published in JAMA by the American Medical Association analyzed data from 39 studies for a total of 85 comparisons of clinical trial participants and routine care patients. The results concluded that cancer patients in a drug clinical trial did not live longer than patients who got the same drug outside the trial. It also found that patients picked for clinical trials may do better than others because they tend to be younger and fitter and have fewer other diseases.

We've been hearing about clinical trials for decades and patients and families often consider them the pot of gold at the end of the rainbow. But what, exactly, is a clinical trial? According to information provided on the Cleveland Clinic Cancer Center website, "cancer clinical trials, also called research studies, test many types of treatments such as new drugs, new surgical techniques or radiation therapy, new combinations of treatments, or new methods. The goal of the research is to find better ways to treat cancer. Cancer clinical trials include research at four different phases. Each phase answers different questions about the new treatments."

In clinical trials, patients receive treatment and doctors carry out research on how the treatment affects patients. A person's progress is closely monitored during the trial. Once the treatment portion of the trial has been completed, patients may be followed in order to gather information regarding specific endpoints. These endpoints are defined prior to the study being started and may include time for disease progression and/or overall survival. Cancer clinical trials include research at four different phases. Each phase offers different questions about the new treatments.

**Phase I Clinical Trials.** These are the first steps in testing a new cancer treatment in humans. The questions being explored are what is the best way to give a new treatment; can this medication be given safely to humans; and what is a safe dose? These trials have a limited number of patients who would not be helped by other known treatments.

**Phase II Clinical Trials.** These focus on learning whether the new cancer treatments have an anti-cancer effect on a specific type of cancer. Additional information regarding the side effects of the treatments is also obtained. A small number of people are included because of the risks and unknowns involved.

Phase III Clinical Trials. These compare the results of people taking a new cancer treatment with the results of people taking a standard treatment. Important questions are which group has better survival rates or fewer side effects? People participating in trials at this level are assigned at random (a process similar to flipping a coin) to either new treatments (treatment group) or the current standard treatment (control group). Randomization helps to avoid bias in a cancer clinical trial. When no standard treatment exists for a cancer, some studies compare a new treatment with a placebo (a lookalike pill/infusion that contains no active drug). However, a person is told if this is a possibility before deciding whether or not to take part in a trial. These trials may include hundreds of people from different centers around the country.

**Phase IV Clinical Trials.** These are also called post-marketing studies, and are trials conducted after a treatment has been approved. The purpose of these trials is to provide an opportunity to learn more details about the treatments, such as mechanism of action, fine points regarding toxicity, quality of life, and questions that may have come up during other phases.

### Possible Benefits of Participating

- Clinical trials offer high-quality cancer care.
- You may be among the first to benefit from a new treatment.
- You have the chance to help others and improve cancer treatment.

#### Possible Drawbacks to Participating

- New treatments being studied are not always better than, or even as good as, standard care. They may have side effects that are unexpected or that are worse than those of standard care.
- Even if a new cancer treatment has benefits, it may not work in your case. Even standard treatments, proven effective for many people, do not help everyone.
- If you receive the standard treatment rather than the new treatment being tested, it may not be as effective as the new approach.
- Insurance companies do not always cover all patient care costs in a study. What is covered varies by plan and by study. [concluded on page 5]

## **Cancer Treatment and Insurance**

In 2024, according to the American Cancer Society, just over two million Americans will be diagnosed with cancer. They will spend on average \$42,000 during their first year of treatment, according to a study in Cancer Epidemiology, Biomarkers, and Prevention. If you get a cancer diagnosis and you have good health insurance coverage, it might cover all or most of your treatment costs.

However, nearly 26 million Americans under age 65 were uninsured in 2022. Many others have high deductibles and copays that make their healthcare unaffordable. Having no health insurance or subpar insurance is not only a financial burden, it could compromise your health outcome.

Being uninsured doesn't mean you have to forgo the cancer treatment you need. Resources are available through your cancer hospital, nonprofit organizations, local agencies, and drug manufacturers to help you pay for care. A first stop might be **healthcare.gov** to see what options are available for you. You might qualify for Medicaid, the state-administered program that offers low-cost or free health insurance plans, if your income is low enough or you have a disability. At age 65 and over you can enroll in Medicare.

If you are being treated but worried about money and therefore considering skipping a treatment, don't. Instead, ask your hospital's billing or financial department if they offer charity care – discounted care for uninsured or underinsured patients.

Some pharmaceutical companies have patient assistance programs that provide their drugs for free or at low cost to people who need them. You can find one of these programs by searching **PhRMA's Medicine Assistance Tool.** 

HOPE is always here to help patients but we can't pay all the bills the cancer family has so here is a list of other places you may seek assistance. Many nonprofit organizations help people with cancer navigate the costs of their treatment and related expenses like transportation and housing.

- CancerCare. This nonprofit organization of oncology social workers offers support, including financial assistance, for cancer patients and their caregivers.
- Cancer Financial Assistance Coalition (CFAC). Enter your ZIP code and diagnosis
  into the search tool, and you'll find many different types of financial assistance, from copays to housing.
- **FamilyReach.** This organization provides free financial assistance and help with navigating resources. (familyreach.org)
- HealthWell Foundation. This nonprofit reduces the financial barriers that stand in the way of underinsured patients getting medical care.
- Hope Lodge. This is an American Cancer Society program that gives people with cancer
  a free place to stay when they travel for treatment.
- Mercy Medical Angels. This organization provides free transportation to medical care across the U.S.
- PAN Foundation. The Patient Access Network Foundation provides financial assistance to Americans with serious illness.

Also, check with your local Department of Social Services to see if they offer help paying for food, housing, or other costs associated with cancer treatment.



"When we do
the best we can,
we never know
what miracle is
wrought in our
life, or in the
life of another."

~ Helen Keller

## Face the Fact—You Need Sunscreen on Your Face

We're approaching the heart of sunscreen weather so here's a little information about sunscreens for your face and a few recommendations, courtesy of *The New York Times* consumer department.

The best sunscreen for your face is the one you'll actually use every day. It's perfectly fine to apply the sunscreen that you put on your body on your face as well, though face-specific formulas can be more comfortable to wear.

#### Here is what to look for:

- SPG 30+ The American Academy of Dermatology suggests choosing sunscreens that advertise a sun protection factor of 30 or higher.
- Broad spectrum Choose a sunscreen that protects against both UVA and UVB rays.
- Price per ounce To be well protected, you need to apply sunscreen liberally and reapply it often.
- A formula you love The best sunscreen for you is the one you'll happily wear every day, rain or shine.

The NYT top pick is **Banana Boat Light as Air Face SPF 50+** sunscreen lotion. "It rubs in really easily, blends well on a range of skin tones, and has a nice, breezy scent." The lotion doesn't take much effort to spread and it stays in place so there is no stinging from a runny formula. It is water resistant up to 80 minutes and the average cost is \$4.00 per ounce.

**Black Girl Sunscreen SPF 30**, despite its name, will appeal to a wide array of people whose skin is prone to dryness. It has a nice, full texture (one tester compared it to Greek yogurt) but takes a little more time and rubbing to fully blend into the skin. It is water resistant up to 80 minutes and its average cost is \$5.33 per ounce.

**Trader Joe's Daily Facial Sunscreen SPF 40** is a clear-gel sunscreen that settles quickly into the skin without feeling sticky. It contains no added fragrance and is nearly unscented. It is water resistant up to 40 minutes and the cost is \$5.80 per ounce. However, not every Trader Joe's store carries it.

As we've reminded in previous years, common sense precautions include avoiding afternoon sun and if you have to be out then seek shade; wearing sunscreen and reapplying it every two hours if you're outside; covering up by wearing lightweight long-sleeved shirts and pants; and never using tanning beds or sunlamps.

## Clinical Trials—Questions to Ask

#### [continued from page 3]

- What are the possible short- and long-term risks, side effects, and benefits of the treatment?
- What kinds of treatments, medical tests, or procedures will I have during the study? And how do they compare with what I would receive outside of the study?
- How long will the study last? Will there be a follow-up after the study?
- Where will my cancer treatment take place? Will I have to be in a hospital?
- How will I know the treatment is working?
- How could the study affect my daily life?
- Will my records be kept confidential?
- Will the study cost me anything?
- If I decide to withdraw from the study, will my care be affected? Will I need to change doctors?

If you're interested in locating a clinical trial one good place to start is **clinicaltrials.gov**, which is part of the National Library of Medicine and lists clinical trials for cancer and many other diseases and conditions. It contains trials that are on the National Cancer Institute's list of cancer trials as well as trials sponsored by pharmaceutical or biotech companies.

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"Of all the forces that make for a better world, none is so powerful as hope. With hope, one can think, one can work, one can dream. If you have hope, you have everything."

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## RETURN SERVICE REQUESTED

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