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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

Support Group Mtg.

Date:Wednesday, July 12Time:7:00 p.m.Location:H.O.P.E. HavenSpeaker:Everyone

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)

50/50 Raffle Take a Swing at Cancer! 15th Annual Golf Classic RAFFLE! Tournament Drawing Held at the Saturday, August 19 Take a Swing at Cancer Hickory Heights Golf Golf Tournament Course (But you don't need to Spring Grove, PA attend to win!) Continental Breakfast, Lunch, Lots of Prizes Donation \$1.00 or 6 for \$5.00 Hole-In-One on #17 Wins \$5,000 for you/\$5,000 for HOPE. Call office to order tickets. Call 717-244-2**174 for info**rmation.

H.O.P.E.'S NEW ADDRESS

Physical Address: 13275 Blymire Hollow Rd., Stewartstown, PA 17363 Mailing Address: P.O. Box 279, Stewartstown, PA 17363 Phone: 717-244-2174

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FROM THE EDITOR'S DESK

HOPE friends and supporters come in all ages and from all walks of life. One friendship that Barb has cherished for nearly 15 years is with the ladies of the Mid-Atlantic Women's Motorcycle Rally (MAWMR). It's doubly meaningful because that's where she first met Carol, who's been Barb's right-hand woman for the past seven years. Every year MAWMR holds a rally; this year was the 31st such event. More than 300 lady bikers attended the three-day event in York where they socialized, took road trips, and raised money for two cancer groups—HOPE and Pink Out. HOPE can't thank these amazing ladies enough for their love and generosity.

The Mason Dixon Car Club held an event at the Dallastown Family Restaurant and donated proceeds to HOPE. The Masonic Temple car show was rained out, but they still gave a generous donation to HOPE. And we thank all of the people who shopped at the Shrewsbury Markets yard sale on Saturday, June 10; over a thousand dollars came to HOPE from that day.

In last month's newsletter we told you about our 2023 high school senior scholarship recipients. We also sent out a request for updates from previous winners. We were thrilled to her from Dixie Miller and Samantha Weekley, two very different young women whose lives have nevertheless taken impressive turns and who give HOPE credit for assisting them and their families through their cancer struggles. Both Samantha and Dixie have earned post-graduate degrees and are thriving in their chosen fields. You can read their updates on the next page of this newsletter.

Usually (fortunately) major nightly news stories are just that-stories that happen to other unfortunate people. Unless the story is about the critical shortage of cancer drugs, a story that has been front and center for months now. One of our cancer patients is experiencing the ramifications of this shortage-the medication that has been working to shrink his tumor has been unavailable and may continue to be unavailable for another month or more. In the meantime he is being given a different drug that is less effective. Medical personnel are as frustrated as their patients. On page 4 we have a short article about the causes of this shortage and how it's being handled.

A few reminders of upcoming events:

- Golf Tournament
- Twin Rose Lady Riders Road Run
- **Bull Roast**
- Fall Bingo •

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

Can you believe that school is out and we are heading into summer? June means MAWMR (Mid-Atlantic Women's Motorcycle Rally) to Carol and I, over 300 women motorcyclists get together to have fun and support two charities H.O.P.E. and Pink Out. It is always wonderful to be with these ladies who are from all over the East Coast. It is like

Saturday, August 19

Saturday, Sept. 23

Saturday, Sept. 30

Sunday, November 5

old home week, especially to Carol because she has been involved since the very beginning, whereas, I have only been going for roughly 15 years. We laugh and carry on but on the last night, it becomes serious when they invite all the cancer survivors to step forward, and then the tears come. I don't have a total yet from our weekend but I will let you know when that total is given to me. While I was with the bikers, Barb Spurlock filled in for me at the Markets at Shrewsbury and those wonderful folks raised \$1000 for H.O.P.E.

"A loving heart

is the truest wisdom."

~ Charles Dickens

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!



Where Are They Now—Two Scholarship Recipients' Accomplishments

It's gratifying to have a small hand in helping our high school seniors start the next phases of their lives—college and beyond! Every now and then we'll hear from or about our former scholarship recipients. Recently we received updates from two of our college grads. HOPEfully after seeing these accounts more of our scholars will reach out with their own success stories.

Hello HOPE Friends:

My name is **Dixie Miller**, and I was a HOPE scholarship recipient in 2015 (from West York HS). Since graduating, I earned a bachelor's degree from Lehigh University in Biological Sciences with minors in Psychology and Health, Medicine & Society. During my time there, I was lucky enough to be a part of the Varsity Women's Rowing Team for two years. I was an orientation leader and a resident assistant, I participated in various clubs and organizations, I held leadership positions in student gov-ernment, and I volunteered regularly at the local hospital. I followed graduation with a gap year, where I worked in a microbiology lab while applying to medical school (and yes, dealing with COVID). In 2020 I began medical school at Penn State College of Medicine in Hershey, PA, and I am currently starting my fourth and final year. I have decided to pursue a residency in OBGYN, and I am excited to see where my next steps take me in my medical career.

All of the progress I have made with my educational career would not have been possible without the help of HOPE and the scholarship I was awarded. You all provided my family with assistance when we were in a time of dire need, and I am grateful for that generosity every day. I love receiving the regular updates from HOPE in the mail and seeing the new scholarship recipients each year.

Since 2015, my father has been in great health, and continues to be in remission. He has taken to advocating strongly for colorectal cancer screening at earlier ages, and he celebrates his progress every year on World Ostomy Day.

Thank you all again for your generosity, and for providing families with HOPE every day.

Hello H.O.P.E Friends!

My name is **Samantha Weekley** and I was a H.O.P.E. scholarship recipient in 2011. I was a graduate of Eastern York High School and went on to a 4-year school named Warren Wilson College in Asheville, NC. I started college not sure what I wanted to do but quickly found Social Work as a calling. I graduated in 2015 with my Bachelor's of Social Work. In my time at Wilson, I completed over 1,000 hours of community service, completed an internship with the YWCA, and worked in the residence life department.

Directly upon graduating from my undergrad, I started my graduate program at Millersville University in Pennsylvania. I obtained a Master's in Social Work in 2017. As a social worker, I was interested in many different populations, including hospice. I used my degree to start working as a Residence Hall Advisor at Thaddeus Stevens College of Technology in 2017. I still work there today.

HOPE was a lifeline for my family during my high school years. In a cruel twist of fate, my mother and stepfather were both diagnosed with brain cancer about six months apart from one another in 2008/9. By the time I received the HOPE scholarship, my stepdad had passed away from his glioblastoma and my mom was still in treatment for her Anaplastic Astrocytoma. During their illnesses, HOPE really provided support and resources to my working-class family. I found a lot of joy in the Christmas presents, activities, and ultimately the monetary scholarship that helped me go to college. I am the only person in my family to graduate college and it was a huge help to receive the scholarship. I moved back in with my mother in 2017 and lived with her until she passed away in 2022.

I am immensely grateful for the role that HOPE has played in my life and enjoy staying up to date with what the organization is doing. I hope this snapshot warms some hearts and reminds us all how important HOPE and its work is.

Thank you, Samantha Weekley

A Troublesome Shortage of Cancer Treatment Drugs

No doubt you have heard about the shortage of chemo drugs; hopefully you haven't been directly impacted by this. According to CNN news "Among some of the nation's largest cancer centers, more than 90% have reported being directly affected by the current shortage of chemotherapy drugs in the United States, according to a new survey." The survey, conducted by the National Comprehensive Cancer Network of 27 cancer centers across the country, reported that the majority are experiencing a shortage of the chemotherapy medication carboplatin and the drug cisplatin. These are used in combination to cure many types of cancer. These drugs are platinum-based drugs and are delivered by sterile injection, which makes them trickier to produce than a pill, and is another reason why they're more likely to suffer a shortage in manufacturing.

The explanation boils down to manufacture of generic, or non-brand drugs, which are not the money-makers for drug manufacturers. As explained by Jeffery Pilz, an assistant director of pharmacy, medication safety, and drug policy for the Ohio State University Wexner Medical Center, "Ultimately, inexpensive (less than \$9 a dose) medications that are only available as generics provide little financial incentive for manufacturers to reinvest in the production line or expand production capability. Even though they are commonly used, many of the traditional chemotherapy agents fall into this category."

During Covid, many factories that produced these drugs shut down and did not reopen, which led the remaining companies in the generic business to cut corners to meet the demand. Intas, a company based in India, made about half of the key cancer drugs used in the United States until last year, when FDA inspectors found evidence of major safety and quality violations and shut them down. This halted the production and supply of key cancer drugs. The FDA last month temporarily allowed imports of a non-FDA approved version of cisplatin (used for breast, ovarian, and colorectal cancers) from a China-based manufacturer and that shortage is starting to ease in some areas.

What are doctors and treatment centers doing? Rationing their supply through various means, including

- Sticking to the lowest recommended dose and the longest accepted interval between doses.
- Looking for other medications that are available with comparable efficacy and safety.
- Trying to get insurance companies to relax prior authorization requirements so patients can get nonstandard treatments.
- 'Triaging' which patients receive the drugs first.

Congress and the FDA are pushing for recommendations and regulations that can advance domestic manufacturing and improve the pharmaceutical supply chain.

Take A Vacation From Cancer at the HOPE Haven

If you and your family are experiencing the challenges of navigating a cancer diagnosis, its treatment or its aftermath, and you need a vacation from the immediacy of its day-to-day travails, the HOPE Haven might be your answer. Nestled on 18 acres of peaceful tranquility, it is a modern farmhouse with three suites, including one that is handicap accessible, and can host up to 10 guests at one time. The grounds include an inground swimming pool, a basketball hoop, a tranquility garden, a fire pit, and walking trails. In addition to guest quarters the inside boasts an open country kitchen/dining room, a living room, a library, and game rooms.

There is no cost for a stay at HOPE Haven, and it's only a hop, skip, and a jump from Shrewsbury and Stewartstown. To learn more about this remarkable community resource visit HopeLifeline.org and apply for an opportunity to spend a



few days with your family at the Haven. Right now there are open dates in both July and August that could fit your family's vacation needs. Call the office (717-244-2174 or 717-244-2354) for more information or to make a reservation.

If you know of anyone who is having a hard time getting the things they need for everyday life in their homes, here is a nonprofit in Red Lion that may be of assistance.

Harold Haney's Barter Barn, 560 Boundary Avenue, Red Lion. Phone 717-683-2310. Open Saturday and Sunday 9 a.m. to 5 p.m., and Wednesday from 1 p.m. to 5 p.m.

Surfing the Net Safely

Where do the majority of us immediately turn when we want more information about a topic? The internet, of course. That goes particularly for medical questions. After all, "Knowledge is power," right?

According to an AARP article in its May bulletin, almost 60 percent of all Americans go online to get medical questions answered, and four in five of us research our medical recommendations online after a doctor appointment. Unfortunately as technology 'improves' and information becomes even more plentiful, the downsides to this type of knowledge increase as well. With the advent of AI, artificial intelligence, 'information' you find isn't always accurate or appropriate. (Recently, the National Eating Disorders Association shut down its new chatbot "Tessa" for responding to a questioner with diet tips on how to lose weight.) As Gary Schwitzer, founder of the former Health News Review website explained, "When you ask a chatbot a question, it pulls information from everywhere online to create an amalgam of data, news and opinion, taking from both traditional and unknown sources. Online publishers use these bots to generate content, including in the health space."

AARP asked some of the nation's leading epidemiologists for the best sites to search following a diagnosis of a medical condition and here are four of them:

- Centers for Disease Control and Prevention (cdc.gov)
- National Institutes of Health (nih.gov)
- American Academy of Family Physicians (familydoctor.org)
- Mayo Clinic (mayoclinic.org)

And here's a site that will direct you to a multitude of cancer information sites broken down into over a dozen different categories, from BIPOC (Black, Indigenous, and People of Color) to Treatment Options: Drugs and Biologics. <u>https://</u> <u>www.mlanet.org/page/recommended-websites-for-cancer-information</u>.

Journaling: "Mindfulness in Motion"

If you've been reading these newsletters over the years, you may recognize the name Suleika Jaouad. Diagnosed with acute myeloid leukemia in 2011, she wrote a column for the *New York Times* titled "Life, Interrupted" and published a best-selling memoir in February 2021 titled "*Between Two Kingdom*," which we excerpted in a newsletter after it was published. Less than a year later, after being cancer-free for a decade, her leukemia returned.

This time she reached out to many followers and readers she had developed (over 100,000) and invited them to join her online in her "Isolation Journals," weekly prompts from "some of the world's most renowned writers, celebrated artists, inspiring community leaders, and unsung heroes." She began the site during the pandemic lockdown as a means of connection and encouragement in her belief in the "power of creative expression to edify, heal, and unite." Here is the website for those who are interested in seeing this site for themselves: https://www.theisolationjournals.com.

What she is suggesting is journaling, something long, long known to be an antidote to many of life's ailments. Here are six benefits of journaling, according to healthline.com:

- Journaling helps to reduce stress.
- Journaling may boost health and well-being.
- Journaling encourages space from negative thoughts.
- Journaling provides a way to process emotions.
- Journaling can help you figure out your next step.
- Journaling deepens self-discovery.



Now that we've got you thinking about trying this, we can help you a bit more. In the HOPE office we have a quantity of inviting journals that we'd love to give to anyone who wants to give writing a try (or any seasoned writers who need a new place to record their thoughts). The book was designed by Beverly Katherine Kirkhart, a breast cancer survivor since 1993, and is a combination of her experiences and thoughts with prompts and pages for writing. Visit Us on the Web Www.hopelifeline.org http://www.hopelifeline.org "Like" Us on Facebook:



"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."

ВЕТИRИ SERVICE REQUESTED

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