

2022-23

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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,

January 12, 2023

Time: 7:00 p.m.

Location: H.O.P.E. Haven

# 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)

Join us for our
Annual Holiday Tea
at the H.O.P.E. Haven
on Wednesday,
December 21st at Noon.



Seating is limited.
Call the office to reserve your seat.
717-244-2174



January 2023
Calendar Raffle
Donation \$20 per ticket

Prizes from \$50 up to \$1000

GIFT CARDS
Diamond Necklace
Visit link to see prizes and
order online.

https://hopelifeline.org/ calendarraffle/

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

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

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#### FROM THE EDITOR'S DESK

Merry Christmas and Happy New Year! We truly hope you will experience both of these in the upcoming months. It's been another challenging year, but as you will read in Barb's expanded Angel Corner below, it's been a year full of blessings for our organization and families.

This issue covers two months (Barb's Christmas present to me). January is cervical cancer month, and it's a cancer that's been written about yearly in our newsletters. Bottom line people: it's become one of the most preventable ones with the advent of the HPV vaccine, which has been available to girls and boys (and people up to age 45) for over a decade. Ninety percent of cancers caused by HPV in the U.S. can be prevented with use of this vaccine. Because we've reported on this cancer and its prevention every year for the past several, our cancer article this issue is one that contains some optimistic updates on what's being done for our littlest cancer patients. On the next page you'll find information about an oncology group that focuses on pediatric cancer and what it has done and is doing to improve outcomes for those patients.

Page four contains a blessing and a Christmas poem, and on page five Barb gives some wise, wonderful suggestions for more meaningful gift giving. And she ends with a beautiful quote that you'll find twice in this issue!

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

Did you notice all the Angels around this year? They were hovering over HOPE for sure, generating support, money, and love! We recognize all the businesses, clubs, organizations, and large donors each month, but what about the **Angels in the background**? These are the people who quietly fill the backpacks every year; attend our fundraisers and bid on silent auction items; make wig stands; work at the Haven getting it ready to open and helping maintain it; donate handmade blankets, quilts, pajamas, hats, etc. It is the Board members who work behind the scene that handle the business end of keeping HOPE running.

Many, many of you have been blessed by **Sandy Sharnetzka**, who writes our lovely thank you notes. Funny story, we got a call from a gentleman who said I understand you still send out thank you notes. I replied yes we do, and his response was then I want to meet with you. After a nice luncheon with Sherman he said, I believe in showing kindness and thanking people and no one does that anymore. So when my neighbor showed me her thank you note I decided I needed to find out about you. He did, and he sent us \$10,000. Sherman passed soon after that but this is a reminder to always show kindness and be thankful!

Another truly behind-the-scenes super volunteer is **Kay Joy**, who keeps us all fed here at HOPE, not just the staff but anyone using the food pantry. Kay makes wonderful meals to freeze for families. Speaking of the pantry, and keeping it stocked, we can't forget our "coupon queen" **Bobbie Seidel**. Bobbie shops every day for HOPE, finding great bargains for the items we provide to our grateful clients. We need to recognize **Herman Hall**, our numbers cruncher, who does the data input into QuickBooks weekly. **Jean Lillquist** keeps you informed in our newsletter, and the ladies listed on the front page gladly assemble it and get it ready to be mailed. If you've called the office you've been greeted by the sunny voice of **Carol Nelson**, my right-hand gal, who puts up with my crazy questions of "how do I do this on the computer?" "how do I spell ----?" and a thousand others.

For many cancer patients and their families, Christmas is anything but a festive time of year. Illness and financial worries take so much of the anticipation and fun out of the holiday. We are blessed every year with families who give Christmas to a cancer family and blessed by local organizations who put up Mitten Christmas Trees with gift requests for our kids. Thank you to J&B's Restaurant, Stewartstown Presbyterian Church, Mason Dixon Baptist Church, Main Street Beauty Works, and Stewartstown Baptist Church. Johnny from Ten Perfect Nails always provides gifts either by shopping for us or donating a check for the volunteers to go shopping for our families. We can not forget our Head Elf, Marty Streett, without whom and her merry band of elves, Lynn Snook, Linda Topper, and Jeannette Keech, Christmas would not happen for our families at HOPE.

Without all these wonderful volunteers HOPE would not have been able to help the thousands of patients that have needed our help over the years. Thank you all for your commitment to HOPE.

May all of you Have a Blessed Christmas Season.

"Blessed are those who give without remembering and take without forgetting."

~ Elizabeth Bibesco



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!

## Improvements in Addressing Pediatric Cancer

Pediatric cancer is fairly rare. In the United States about 16,000 children under 20 years of age are diagnosed with cancer every year. By comparison, 1.9 million adults are diagnosed with cancer each year. Because of this, progress in pediatric cancer has been noticeably slow. However, a group known as COG, the Children's Oncology Group, has changed this. COG is a network of researchers and hospitals that have contributed to improvements in the treatment of children with cancer and the continued increase in cure rates for several childhood cancers. It was formed in 2000 through the merger of four childhood cancer research organizations and has about 1000 active clinical trials studying potential new treatments and ways to improve existing treatments at any given time. These trials often include related studies to help researchers better understand the biology of childhood cancers.

The goal of these doctors and researchers is to cure and restore their little patients to lifelong health. For a child who's treated at age three, the goal is to give them 70 or 80 more years of life. Long-term side effects of treatment are also a major consideration. The consequences of giving brain radiation to a three-year-old compared with a 43-year-old are dramatically different. Likewise with growth; radiation delivered to a child's bone or limb can affect its growth. On the other hand, children's organs – their heart, their lungs, their kidneys – are healthy to start with, so they may actually be able to tolerate more intensive treatment. These are all issues COG focuses on with its patients and research.

A good example of addressing the issue of long-term side effects is the use of radiation. Giving radiation to the brain is associated with long-term learning and developmental problems. In one type of leukemia, T-cell ALL, radiation had been given to the brain in more than 90% of patients. COG reduced that rate to 9.5% and there was no difference in the cancer outcome. In an upcoming study, treatment for Hodgkin lymphoma, one of the most common types of childhood cancer, will be addressed. It has a very high cure rate but a lot of kids have lasting side effects not only from radiation but also from some of the chemotherapy medicines, one of which can affect the heart. In this upcoming study doctors will test reducing the amount of chemotherapy by substituting a combination of two immune-oncology drugs. The hope is that they can maintain the high cure rate for Hodgkin lymphoma but eliminate the long-term effects of treatment on the heart.

A major development in the treatment of childhood leukemia is CAR T-cell therapy. In this relatively new treatment a patient's T cells (a type of immune system cell) are changed in the laboratory so they will attack cancer cells. T cells are taken from the patient's blood. Then the gene for a special receptor that binds to a certain protein on the patient's cancer cell is added to the T cells in the lab. The special receptor is called a chimeric antigen receptor (CAR). Large numbers of CAR T cells are grown in the lab and given to the patient by infusion and once in the patient the CAR T cells bind to cancer cells and kill them.

A recent successful clinical trial involved treating children with ALL (acute lymphoblastic lymphoma), an aggressive type of leukemia in which too many immature white blood cells, known as B-cell lymphoblasts, are present in the bone marrow and blood. Standard initial treatment for children and other younger patients diagnosed with B-cell ALL is chemotherapy to put their cancer into remission. If the cancer comes back after the initial therapy, the patient is given chemotherapy again and may go on to a stem cell transplant. However, if the patient experiences severe side effects this transplant procedure may not be possible, which increases the likelihood of the leukemia returning. Here is where a new drug, blinatumomab, came in. Patients in trials in America (ages 1-30) and Europe (ages 1-18) who were treated with blinatumomab had greater chances of remaining in remission and being cured and suffered fewer side effects.

A drug approved by the FDA in 2015 is dinutuximab, for treatment of children with neuroblastoma, a cancer of immature nerve cells in the brain. Although rare it is also deadly, and only 40 to 50 percent of patients with high-risk neuroblastoma survive the disease. Five years after being treated with dinutuximab, 72% of children in a clinical trial of 1,200 children were still alive and 61% had no evidence that their cancer had come back or their tumors had grown.

COG is funded by the National Cancer Institute and is part of its National Clinical Trials Network. COG includes about 230 institutions, most of them in the U.S. In Pennsylvania, you can find them at the Children's Hospital of Philadelphia, the Children's Hospital of Pittsburgh, Penn State Hershey Children's Hospital, and several other locations.



Did you know that the arrival of this newsletter every month in your mailbox is a gift from HOPE? We understand that many of you (over a thousand) still love to read the 'hard' copy rather than peruse it online; we also realize there are those who cannot access it online. Nevertheless, the paper and ink and postage take a chunk out of our finances, and unfortunately it's a double jeopardy when we pay the postage to mail an issue but then the post office is unable to deliver it and charges us again for its return! This is costing us an extra eight to ten dollars a month.

We are asking you to please let us know if your address is changed or you no longer wish to receive the newsletter in the mail. Thank you!

# A Blessing For Those Who Are Living With Pain

Kate Bowler has made many 'appearances' in this newsletter. She is one of my favorite podcasters and a is wise, witty woman. She is a Duke University history professor, an author, podcaster, speaker, mother, and cancer patient. At age 35, in 2015, she was diagnosed with Stage IV colorectal cancer, and since then she has undergone countless surgeries and years of immunotherapies. Her podcasts are conversations with medical people, writers, religious leaders, celebrities, athletes, anyone who can help us with our struggles in life. At the end of each she offers a blessing based on the theme of that episode. Her conversation with Dr. Haider Warraich, titled "Embracing the Complexity of Pain." concluded with this 'blessing.'

"We can feel so trapped, so trapped in the bodies we have, the days we have, the discomfort and 'What does this mean for the trip I had planned on?' feelings. Whether we can hold the people we want to hold and expand our world. And I know that everyone is going to try to rush for a solution for you for pain. Instead of doing that, let's just try to see everything we can from where we stand. Let's bless it, which is to say try to put it in its place even if it's out of place. So here's a blessing for if you are in pain and your body feels like the enemy.

"Blessed are you on this pain-filled day.

When getting out of bed seems to be an award-worthy triumph.

When you can't remember what it feels like to not be so aware of your own body.

When you arrange your weeks around appointments or side effects.

Or when you stop telling the truth altogether about how badly it hurts, how scared you are of your own mind or the boring details of another non-diagnosis, because you're afraid people have stopped caring. You speak a language of suffering the world doesn't try to understand. So blessed are you whose world has shrunk to a space so small it's defined most by what is no longer possible.

You count, and so does your pain. It does not and did not disqualify you from belonging. For the truth of it is that life is painful, and what makes it so is the beautiful and terrible living side by side, our loves and our losses."



"The joy of brightening other's lives, bearing each other's burdens, easing other's loads, and supplanting empty hearts and lives with generous gifts becomes for all of us the magic of Christmas."

~ W. J. Jones

## Christmas

Author Unknown

Every time a hand reaches out to help another, That is Christmas.

Every time someone puts anger aside And strives for understanding, That is Christmas.

Every time people forget their differences And realize their love for one another, That is Christmas.

May this Christmas bring us
Closer to the spirit of human understanding
Closer to the blessing of peace.



## Suggestions For a Special Holiday Season

Everyone goes crazy trying to buy the most wonderful gift, but that is different for everyone. What you think might be the perfect gift for your loved one might not be what they need at all. So, before you buy a bunch of "stuff" for family and friends, try asking them what they might need.

- Maybe they need help with their utility bill, car payment, or rent. With prices soaring everyone is struggling a little.
- Maybe they need a kid-free night and could use a free babysitter.
- Maybe they need gas for their car to go to treatment or work.
- Maybe they need a night off from cooking and could use a homemade meal or a gift card to a local restaurant. It doesn't have to be an expensive restaurant, any fast food would work. Just so they don't have to cook.
- Maybe they need a cup of tea and someone to listen. Remember you are there to listen not burden them with your problems.
- Maybe they need a fun night out.
- Maybe they just need a visit; so many are alone and need companionship. A gift of time is priceless!
- Maybe they need help decorating for the holidays.
- Maybe they need help buying groceries. Some of our patients will buy dog or cat food for their furry friends and skimp on food for themselves especially if they are alone. Don't judge them for this, but instead help them by buying them some staples for their pantry shelves or give them pet food so they can buy the food they need. In my family, we give fun food baskets. I like to buy a container that can be used later and fill it with what each individual family member likes. Make sure that there is at least one thing that is "special" for that person. If they are a cancer patient remind them HOPE has a food pantry!
- Maybe you could be the one to give them what they really need this season, rather than more "stuff."

A few years ago, Christine Peck spoke at our December support group meeting on how Christmas changes with time and how difficult it is for those grieving. She shared these thoughts: "Holidays change for all of us over time and the greatest gift God gives us is memories. We can cherish and share our memories with one another, especially on holidays and special occasions" So, if you are grieving this holiday season be kind to yourself. If you can't put up the tree that is okay. It is okay not to do everything you have done in the past; you can make new traditions.

W.C. Jones wrote, "The joy of brightening other's lives, bearing each other's burdens, easing other's loads, and supplanting empty hearts and lives with generous gifts becomes for all of us the magic of Christmas."

May you and your family experience life's greatest gifts this year-hope, faith, happiness, family, and friends.

## 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."

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