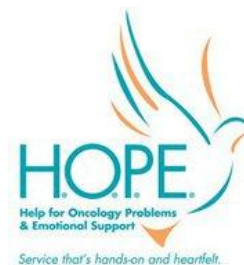




August 2017

H.O.P.E. LIFELINE



H.O.P.E.
Executive Director
Barb Titanish
Assistant Director
Carol Nelson

Board of Directors

Doug Burns—Chair
Buddy Hart—Vice Chair
Cheryl Schroeder—Secretary
Jack Tillett—Treasurer
Sue Holtzinger
Melissa McDade
Sally Miller
Debra Smithson Peters
Robin Robinson
Katelyn Smith
Barbara Spurlock
Vicky Stake

**H.O.P.E. Lifeline
Production Volunteers**

Jean Lillquist—Editor
Carol Slaven—Managing Editor
Jo Huber
Linda Johnson
Kay Joy
Jeannette Keech
Mae Liggitt
Cindy Moran
Lynn Snook
Marty Streett
Rita Stephenson
Linda Topper

H.O.P.E.
P.O. Box 175
Shrewsbury, PA 17361

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 with offices on the second floor of the New Freedom Community Center at
150 East Main Street, New Freedom, PA 17349

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) 227-2824

Take a Swing at Cancer! 9th Annual Golf Classic Tournament

Saturday, August 19



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 717-227-2824 for
information

Shrimp and Bull Roast Saturday, September 23 7—11 p.m.

Jarrettsville Gardens
Jarrettsville Fire Hall

All You Can Eat Buffet
Shrimp, Pit Beef,
Pit Turkey, Sides



Beer and Wine
Silent Auction, Door Prizes
DJ and Dancing

Tickets \$40

Special—Purchase 9 tickets
before August 25th, get 1
free and a reserved table.

Support Group Meeting

Date: Wednesday, August 9
Time: 7:00 p.m.
Location: H.O.P.E. Serenity Room
Speaker: Nick Gohn
Topic: Physical Therapy

INSIDE THIS ISSUE...

From the Editor's Desk	Pg. 2
On A Positive Note	Pg. 2
Angel Corner	Pg. 2
Survivorship	Pg. 3
Online Support Communities	Pg. 4
Chomper Buddies	Pg. 5
What's Happening	Pg. 5

H.O.P.E.'s Office Hours are
Monday through Friday, 9:30—3.
Please call in advance to set up an
appointment for:

- Intake
- Wigs/hats/scarves
- Pantry

Please direct all calls to the
H.O.P.E. office at 717-227-2824.

FROM THE EDITOR'S DESK

Everywhere you look this summer you'll find a little bit of H.O.P.E. Music lovers enjoyed our blow-out music festival at the end of July in White Hall with three bands and lots of great food. On August 1 you can meet your local police officers at the National Night Out at the New Freedom Community Center and feast on great food courtesy of Kim's Smokin' Coals BBQ, with a portion of those proceeds coming to H.O.P.E. Later this month is the Sunflower Festival at the Maple Lawn Winery in New Park. Make sure you purchase your ticket in advance online so that H.O.P.E. can benefit from the ticket cost. (See ad on page 5.) Also in August is the duffers' delight: the annual Take a Swing at Cancer Golf Tournament at Hickory Heights Golf Course in Spring Grove. Our ninth one; they just get bigger and better and more fun. There's still room for more golfers so sign up soon. (See front page.) Finally, looking a bit ahead, H.O.P.E. presents its annual Shrimp and Bull Roast at the Jarrettsville Volunteer Fire Hall. Another H.O.P.E. tradition and popular event so call soon for your tickets. (See front page ad.)

August signals back-to-school preparations. For our cancer families the normal excitement of new school supplies is tempered with the new reality of medical expenses. It's costly to send a child back to school with even the most basic supplies, and for this reason we provide backpacks filled with all the essentials plus a gift card for a new outfit for our cancer family kids. This is only possible through donations and event support. It's win-win for you when you attend one of these events: you have a great time, meet new people, and help a family affected by cancer.

ON A POSITIVE NOTE

By now you've probably heard about Emily Whitehead, if not by name, by her cancer success story. The 12-year-old was diagnosed with acute lymphoblastic leukemia (ALL) in 2010 and nearly died. She had relapsed twice after chemotherapy and doctors had run out of options. Desperate to save her, her parents found an experimental treatment at the Children's Hospital of Philadelphia. This treatment had never been tried in a child or anyone with the type of leukemia Emily had. To perform it doctors removed millions of her T-cells (a type of white blood cell) and inserted new genes that enabled the T-cells to kill cancer cells. These new genes carried a disabled form of H.I.V. because it is very good at carrying genetic material into T-cells. The new genes then programmed the T-cells to attack B-cells, a normal part of the immune system that turn malignant in leukemia.

Fast forward to now. This month the FDA unanimously voted approval for this treatment, which genetically alters the patient's own cells to fight cancer. It will be the first gene therapy ever to reach the market. To use the technique a separate treatment must be created for each patient. The cells are removed and then frozen and shipped to a Novartis plant (the drug company pioneering this procedure) for thawing and processing, then frozen again, and shipped back. A single dose has brought long remissions, and possibly cures, to scores of patients in studies who were facing death because every other treatment had failed. The FDA panel recommended approving the treatment for B-cell acute lymphoblastic leukemia that has resisted treatment, or relapsed, in children and young adults aged three to 25.

It is not inexpensive (\$300,000), comes with side effects, and will not work for everyone with the disease, but it is a ground-breaking first step that should encourage more people and companies to continue researching and developing products like this.

H.O.P.E.'S ANGEL CORNER

BY BARB TITANISH, EXECUTIVE DIRECTOR & CO-FOUNDER H.O.P.E.

Ninety-degree temps and the threat of rain didn't keep everyone from having a great time at the Music Fest on Sunday. Thanks go out to Jackie and Shane Smithson and their family for providing their beautiful Pond View Farm as the venue for an afternoon of music, dancing, and great food, also courtesy of Jackie and Shane. Of course it wouldn't have been a music fest without music, and what music it was. Dakota, Kitty Back, and Foggy Hollow played country, bluegrass, and classic rock toe-tapping tunes. Thanks go to Doug Kreiss, a member of Foggy Hollow, who lined up these great bands that performed for free. Of course events such as this don't pop up magically, and Wanda Mergler and her committee of Melissa McDade, Deb Peters, Robin Robinson, and Cheryl Schroeder spent hours and hours and then more hours organizing and overseeing the event. Delicious, homemade baked goods were provided by the Norrisville United Methodist Church. As ever, everyone's favorite ice cream family, the Summers, provided probably the most popular food item of the afternoon. Finally, we thank the Harford County Sheriff's department for providing security and the Norrisville Ambulance Company for being on hand just in case the heat proved too much. Whew, those are some pretty remarkable people who have earned Angel Wings.



*“Optimist:
someone who
figures that
taking a step
backward is
not a disaster,
it’s more like a
cha-cha.”*

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!

PROBLEMS DON'T END WHEN TREATMENT DOES

Survivorship. This is a term applied to people who have finished with their cancer treatment. Yet they haven't finished with worry and fear, and ironically, their worries and fears may even intensify. Now what? How often should I see my doctor now? Why am I still tired? Should I still have pain and what can I do to control it? Why can't I remember things like I could? What can I do to lose the weight I gained during treatment? Why does my family treat me differently than they did before I had cancer? What if the cancer recurs?

All of these questions arise among cancer survivors. The cancer may have been eradicated but the after-effects linger. Some are short-term; some may be there for the remainder of the survivor's life. Here are some of the more common health issues people face:

- Fatigue
- Sleep changes
- Cognitive problems ('chemo brain')
- Lymphedema: pain and swelling in the arms, legs, or trunk
- Neuropathy (nerve damage)
- Pain

The online Cancer Support Community website has the following excellent advice for cancer survivors:

"As you move beyond cancer, it is important to continue to maintain a healthy lifestyle.

- Don't smoke. If you smoke, talk to your doctor about quitting.
- Get proper nutrition. A healthy diet will help you keep off pounds. This is important because studies have shown that gaining weight after completing cancer treatments may increase your risk of cancer recurrence.
- Exercise. Keep moving. Walk. Do yoga. Swim. Garden. Being active will help you keep the weight off and may help prevent a cancer recurrence.
- Pay attention to your emotional health. Life after cancer treatment isn't always easy you may experience a rollercoaster of emotions after treatment ends, including fear of recurrence. You may be sad or angry about the way cancer has affected your life. If you need to, talk to a counselor or psychologist or join a support group. Within the cancer community, there are others who will understand your experience and what you are feeling.

There are many other online support organizations that offer help for navigating cancer survivorship. The most valuable tool they provide is a **survivorship care plan**. This is a complete record of cancer history, treatments given, the need for future checkups and cancer tests, possible long-term effects of the treatment, and ideas for staying healthy. The plan needs to identify which health care providers are responsible for your care. Most of these begin with the original diagnosis and cover the cancer type, stage, and treatments. They then include a proposed schedule for follow-up visits and other recommendations. A fantastic resource you might want to pull up is offered by ASCO (American Society of Clinical Oncology) at this site: http://www.cancer.net/sites/cancer.net/files/cancer_survivorship.pdf.

Another helpful guide is from the Minnesota Cancer Alliance, "What's Next? Life After Cancer Treatment." This booklet is a road map of sorts, a way to help you record where you've been and provide information to help you plan the next part of your cancer journey. http://mncanceralliance.org/wp-content/uploads/2013/07/SurvivorCarePlan3202012_Final.pdf

Other helpful sites are journeyforward.org, cdc.gov/cancer/survivorship, cancer.org (this one has a separate post-treatment plan for young adults ages 20-39), and cancersupportcommunity.org.

Two H.O.P.E. family members are all too familiar with the stresses that come with cancer and its aftermath. These stresses do ease with time, but the fear of recurrence is always there. One cancer survivor, Pat Smith, likened her state after she finished treatment to one of PTSD; she said you're so busy fighting and then all of a sudden you are done, and the realization of what you've been through hits you like a ton of bricks. She found help in a stress reduction program that emphasized breathing, meditation, and journaling. She also found help through friendships with women who had been through the same nightmare.

Buddy Hart, a H.O.P.E. Board member and cancer survivor, shared the following. "The most important thing after treatments (after rediscovering your taste buds that is), is to remember that it's okay to worry. We often find ourselves overanalyzing every minor imperfection that crops up. Get it checked out. We should all have learned by now that nothing should be overlooked. I've been scared. Repeatedly. I went to the doctor about a lump on my back that turned out to be a stress knot. Even over a decade later I remain cautious. The chance that it could end up being something much worse is not worse the risk." Buddy added that one of the greatest pleasures he had after treatment had concluded was dousing his food in hot sauce. He said, "We often take for granted such simple things but if anything has been learned it should be that not a rock nor a flower or the song of a bird should be missed. It should be soaked in like waves on a beach or ice cream on the tongue."



“When I became ill, the years of pain and confusion loomed up like some primitive monster of the deep...I lived in fear of dying. The strange paradox is that by confronting my fear of death, I found myself and created a new life.”

- Lucia Capacchione

Online Support Communities

Online communities let you create a personal profile where you share information about yourself for others to view. You choose whom to invite or allow access to your profile. Online communities offer numerous benefits for people with cancer.

In an online community, you can post a picture or video of yourself and share updates with people in your network whenever you choose. You are free to decide how much information you are comfortable sharing with others. Several sites offer privacy settings and tools, which let you control who can view your profile and what they can see or read. When creating a profile, learn about the privacy settings and options the site offers to understand how your information is used and how it can be accessed, so you will feel more comfortable when sharing your profile.

If you have thought about joining an online community, here are some options.

4th Angel Mentoring Program provides free, one-on-one, confidential telephone support for people with cancer and their caregivers. Trained mentors who are cancer survivors or have been a caregiver to a person with cancer offer support and guidance during a difficult time.

Inspire features groups for people with cancer and their caregivers. You can also join groups for other health conditions besides cancer. Once you join a group, you can post questions and comments on discussion boards and connect with other group members. Help other members and give encouragement by responding to their stories and questions. Several patient advocate organizations feature support communities on Inspire.

MyLifeLine.org provides free websites for people with cancer and caregivers to keep family and friends updated. Sharing a web page helps reduce the number of times you have to repeat similar conversations to people concerned about you. A calendar on the site helps you keep track of doctor and treatment visits and other important appointments. Plus, you can post requests for help, such as rides to appointments, babysitting, or donations.

Cancer Support Community is an international nonprofit dedicated to providing support, education, and hope to people affected by cancer. They provide support services through a network of professionally-led community-based centers, hospitals, community oncology practices, and online.

CaringBridge helps you create a free, private, and secure web page, communicate updates in a patient care journal, share pictures, and coordinate help.

Cervivor is a community, a learning tool, an advocacy resource, and an online retreat for healing, connecting and thriving.

Friend for Life Cancer Support Network is a network of cancer survivors and caregivers who provide compassionate, one-on-one support to others diagnosed with cancer and to their loved ones.

Know Cancer is dedicated to connecting, educating, and empowering all people affected by the many forms of cancer. It offers an online community that provides social and professional support to patients and their loved ones.

Navigating Cancer is a free website specifically for cancer patients and their supporters, offering tools and cancer resources that empower patients to take control of their health and partner more closely with their physicians, support network, and other like patients.

Peer Support Network provides online support for people newly diagnosed with cancer, cancer survivors, and caregivers. They offer a free, global network that connects people impacted by cancer with others that have gone through similar experiences and is available to anyone looking for or offering support.

Smart Patients is an online community where patients and their families affected by a variety of illnesses learn from each other about treatments, challenges, and how it all fits into the context of their experience.

H.O.P.E. Has Partnered With Community Aid
(Neighbors Helping Neighbors) to Collect Clothing.

We Need Your Clothing, Shoes, Bedding,
Curtains, and Drapes.

These Items Will Benefit H.O.P.E. With
Every Pound You Donate!

(No Small Appliances or
Furniture, Please.)



The Container Is In the H.O.P.E.
Parking Lot. Four More Containers Will Be Located in
Shrewsbury and Stewartstown
Later This Year.

Annual Craft & Vendor Show

Saturday, October 21

8:30 a.m.—2 p.m.

New Freedom Community Building

50+ Crafters and Vendors

Lots of Holiday Gifts!

Tasteful Occasions Fantastic Food

Admission: Two Cans of Food for the Food Pantry

Please check your expiration dates!



New Freedom Farmer's Market

Every Saturday from May through October
10—1

150 E. Main Street, behind Rose Fire Company

Now accepting EBT cards. Local Vendors

- Produce
- Jams and Jellies
- Flowers and Plants
- Breads and Baked Goods
- Handmade Crafts

New Freedom Kids' Farmer's Market

Saturday August 5, 10—1

Kids get a free space to sell anything they grow, make,
or create in any way. Parents may help with set-up but
only the kids can sell. No need to sign-up or register
in advance, just show up at the Farmer's Market be-
tween 9:30 and 10 a.m. to get your space. Bring your
own table, chair, and product(s). Shoppers are also
welcome!



It's a Sunflower Festival!
Maple Lawn Winery
2885 New Park Rd, New Park,
PA

Saturday, August 12, 10 a.m.—6 p.m.

Sunday, August 13, 1 p.m.—5 p.m.

Tickets are available at

<http://www.sunflowerfestivalpa.com>

Use promo code HOPE17 and H.O.P.E. benefits!

It's a Camp-Out!

Friday, August 4 (all night)

Smith Wood (behind Rose Fire Company)

Bring your tent, sleeping bags, board games

150 E. Main Street, New Freedom

(the Community Center will be open for restroom
use)



- Hot dogs and s'mores
- Stories around the campfire
- Morning yoga and breakfast available for purchase
- Fun for the whole family

Chomper Buddies

"If you have a little worry and you don't
know what to do,

Let this Chomper be your friend and he'll
look after you.

Write your worries on some paper, 5 or 6 of
just a few,

Put them in the Chomper's mouth and let him chomp and
chew.

He will eat up all your worries and the things that make you
blue.

And then, before you know it, you will feel as good as new!"



These pillow friends are for children who are anxious or worried
and aren't able to verbalize their concerns. The Chomper
Buddy comes with a pad of paper and a pen, and children write
down their fear, feed it to the Chomper and zip his mouth
closed, and he chomps the fear away. Parents are then able to
talk to their child once they know what is of concern.

Handcrafted by Nancy Ransom, a H.O.P.E. volunteer, Chomper
Buddies can be purchased in the office or online at [etsy.com/
shop/JustFourKids](http://etsy.com/shop/JustFourKids), or through email at [just-
fourkidsllc@gmail.com](mailto:just-fourkidsllc@gmail.com).

Visit Us on the Web
<http://www.hopeforcancerfamilies.org>
"Like" Us on Facebook:
H.O.P.E. (Help for Oncology Problems and Emotional Support)

Upcoming Events

H.O.P.E.'s Support Group Meeting
2nd Wednesday of every month at 7pm
H.O.P.E.'s Serenity Room in the New Freedom Community Center
150 East Main Street, 2nd Floor (Elevator Available)

Everyone is Welcome!
(Cancer patients, care givers, families and friends)
Need transportation to the Support Group Meeting?
Call 717-227-2824



Labor Day

"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."

Nonprofit Org
U.S. Postage Paid
Permit No. 61
Shrewsbury, PA 17361

H.O.P.E.
Help for Oncology Problems & Emotional Support
16580 Green Valley Court
Stewartstown, PA 17363
(717) 227-2824
RETURN SERVICE REQUESTED