

**SEPTEMBER 2018**

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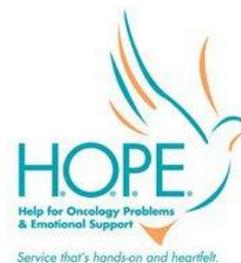
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H.O.P.E.  
P.O. Box 175  
Shrewsbury, PA 17361

# 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 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

## Shrimp and Bull Roast

**Saturday, October 6**

**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 September 14, get 1  
free and a reserved table.**

**717-227-2824**



## Annual Craft & Vendor Show

**Saturday, October 20**

**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**



## Support Group Meeting

Date: Wednesday, September 12

Time: 7:00 p.m.

Location: H.O.P.E. Serenity Room

Speaker: John Malone; Caring Matters

Topic: Care for the Caregiver

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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

We called last month's newsletter the "feel good issue," based on the article about medical marijuana and the latest discovery of the benefits of eating chocolate. This month's newsletter has nothing feel good about it. September is **Childhood Cancer Awareness month**. Of all the thousands of cancer patients Barb has worked with in the 25 years of H.O.P.E., children break her heart over and over again. The unfairness of cancer knows no age limit, and even the children who are "cured" aren't really; many face a lifetime of side effects from the treatment, both physical and psychological. In this newsletter we'll talk about childhood cancer. Here are a few sobering statistics to keep in mind:

- Childhood cancer kills more children than all other diseases combined. Forty three kids a day in the U.S. receive this diagnosis.
- Yet all types of childhood cancers receive only 4% of the U.S. federal cancer research funding.
- The average age of a cancer diagnosis for a child under 15 is six; the average age of death for a cancer child is eight.
- Worldwide, 300,000 children will get cancer this year.
- Childhood cancers tend to be more aggressive than adult cancers.

Did you know the international symbol for childhood cancer is a gold ribbon? The color gold will be on display in Washington, D.C. the weekend of September 15 and 16. **Curefest For Childhood Cancer**, whose mission is to make childhood cancer research a national priority, is holding its weekend rally and will feature a candlelight vigil, a walk, games, activities, and many live entertainers. On Saturday night over a thousand people are expected to gather in front of the White House to honor those who have died too soon from this terrible disease. All are invited to participate in part or all of this moving weekend.

We're trying something different this month and we hope to continue it in ensuing newsletters. We're reaching out to our readers and patients and their family members to tell their stories. This month you will read personal accounts on page 4 from two teenage boys who battled cancer and on the next page from the mother of one of those boys. If you would like to share an aspect of your cancer experience with our readers, be it as a former patient, current patient, family member, or caregiver, please send an email to us at [barb@hopeforcancerfamilies.org](mailto:barb@hopeforcancerfamilies.org). Information is always helpful, but sometimes the best advice and guidance comes from someone who is sharing your struggle.

### A FEW BOOKS ABOUT CANCER IN KIDS (AND OLDER)

Many of you probably remember the regular book review we featured in each newsletter issue. Despite no longer mentioning specific books, we want to remind you that our library is full (overflowing) with books that Barb continues to add to our collection. This month is a good time to mention some excellent resources we have for children and teens about childhood cancer.

#### Books for Children:

*"What About Me? When Brothers and Sisters Get Sick"* by Allan Peterkin, MD

Written for children ages four to eight.

*"You and Leukemia, A Day at a Time"* by Lynn S. Baker, MD

Written to be read by most children eight or nine and understood by children of all ages.

*"Living With Leukemia"* by Patsy Wescott

Three children's stories (ages 12, 10, and 5) about living with leukemia.

#### Books for Teens

*"Teenage Cancer Journey"* by Kathleen A. Gill, a survivor of teenage cancer

*"Planet Cancer,"* by Heidi Schultz Adams and Christopher Schultz

An honest, down-to-earth guide to living with cancer, from diagnosis to post-treatment.

*"The Fault in Our Stars"* by John Green

Fiction best-seller (and blockbuster movie) about two teens with cancer.



*"Every three minutes, a child somewhere in the world is diagnosed with cancer."*

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 [asstant@hopeforcancerfamilies.org](mailto:asstant@hopeforcancerfamilies.org), and she'll put you on our list. (And it will have color!)  
Thanks!

## Childhood Cancer Is Often For Life

We all know that children are not merely miniature adults. This holds true especially in the diseases they can get. Pediatric cancers are very different from adult cancers. When an adult gets cancer, it is likely to start in the lungs, breast, colon, prostate, or skin. When a child gets cancer it may be in the white blood cells or the nervous system, in the brain or bones, in the lymphatic system, muscles, or kidneys. Many times the cause of a childhood cancer is not known, whereas with adults the cancer is often linked to lifestyle choices including diet and smoking. Cancer in children can be hard to recognize right away because early symptoms are often like those caused by much more common illnesses or injuries. In 80% of cases, the cancer has already spread to other areas of the body by the time it is diagnosed. Childhood cancers also tend to be more aggressive than adult cancers. Treatments are different due to the child's age and physical development as well as potential long-range effects from certain types of treatment. Finally, it is hard to study childhood cancer because it is comparatively rare, making up less than one percent of all cancers diagnosed each year.

Many childhood cancers have much higher survival rates when they are diagnosed in the early stages of the disease. Unfortunately, childhood cancers are sometimes overlooked or misdiagnosed because early symptoms are mistakenly attributed to more common injuries or illnesses. It is recommended that children have regular medical checkups, and that parents pay close attention to the development of unusual signs or chronic symptoms, such as:

- Persistent fever, nausea, or illness, often accompanied by vomiting
- Tendency to bruise easily
- Unusual lump or swelling (particularly around the neck, abdomen, chest, pelvis, or armpits)
- Loss of energy and pale complexion
- Headaches, often with early morning vomiting
- Lingering pain in one area of the body
- Abrupt vision changes
- A whitish color behind the pupil
- Sudden weight loss
- Limping

Today, the overall five-year survival rate for childhood cancer is over 80%. However, that does not come without a cost. Two-thirds of those who do survive face at least one chronic health condition. One quarter of survivors face a late effect from treatment that is classified as severe or life-threatening. Late effects of treatment can include heart damage, second cancers, lung damage, infertility, cognitive impairment, growth deficits, hearing loss, and more. It is becoming increasingly apparent that childhood cancer is 'for life.' Late effects from either the disease or aggressive treatment regimens are given at a time of life when children have growing bodies and developing brains. Therefore it is imperative that all survivors of childhood cancer receive ongoing monitoring and continued physical and psychosocial care throughout their adult lives.

### ***“We Are Here For Each Other” - Teenage Cancer Patient’s Mom Andrea Josey***

When our son was diagnosed with Acute Lymphoblastic Leukemia at the age of 17, it was like the rug was ripped out from underneath of us. Suddenly what was a busy life deciding on what college he was going to attend, when he was going to take his SATs again, when his next football camp was going to be, and what color he was going to wear for prom, became replaced with bone marrow aspirations, spinal taps, and chemotherapy sessions. Life as we knew it was on hold for what seemed like an indefinite amount of time.

However, through all the unpredictability there came an unexpected light—friendships—that were like none we ever knew. Out of the despair came families that sadly were already navigating this terrifying journey and were there without being asked to help lead us through the daunting battle we were about to fight. Without us even realizing it, they were arming us with what would be most helpful during the last three and a half years of our lives. Whether it was helping to show us where things were located in the hospital, teaching us the tricks of how to make just about anything in the microwave, what exactly to pack in our hospital bags for long stays, help checking our families into the Ronald McDonald house, or where the washer and dryer were located. But the most important thing these families were there for was a shoulder to cry on when we just didn't think that we could go on. They were there to be our cheerleaders. They knew our needs when we had no idea what we needed, because they had been exactly where we were.

For those who are in the beginning of this battle, we are your family. We are here for each other. I am sorry you are here, but there is no other group of friends that will so quickly become your family.

## In Their Own Words: Two Young Men Talk About Their Cancer Journey

### Marcus Josey

I was diagnosed with acute lymphoblastic leukemia on April 10, 2015. I was 17 when I was diagnosed and nearing the end of my junior year of high school. I am now 20 years old and have just finished my treatment for ALL on August 16, 2018. Although my treatment has ended, my journey with cancer is long from over.

Going into my treatment, back in 2015, I thought that ringing the bell at the end would mean that I was done with everything and my life would go back to how it was. Many people had told me that things would never be the same and to expect a “new normal,” but experiencing this first hand is much different than listening to people’s advice. Many cancer survivors had warned me about the uneasy feeling that comes toward the end of treatment, but I did not expect to face mental and emotional battles as my battle with cancer was coming to an end.

Even though my physical health was improving, the reality of long lasting side effects, depression, anxiety, and PTSD informed me that my life would never go back to normal.

If I were to give advice to another teenager or child going through cancer treatment, I would encourage them to keep a positive mindset throughout treatment and also be extremely vocal about what you are going through with your family, friends, and anyone else who may be a factor in your life. I think sharing your experiences, both positive and negative, can make your journey easier and it also allows people who are not in the “cancer world” to understand the truth about your cancer. Lastly, don’t be afraid to reach out to people if you are struggling.

During my treatment, I decided to go to Gettysburg College with almost two years left in my treatment. When in college, I felt as if no one understood what I was going through and I felt isolated. Something that helped me a lot during those times was reaching out to other cancer patients and even getting involved in young adult cancer organizations such as First Descent. Being around others who knew what I went through made me more hopeful and helped my mental health extremely.

Cancer has made a huge impact in my life, and even though I have had rough times I do not regret anything I have experienced. In the long run I have learned a lot from my journey and I have learned life lessons that I would not have otherwise.

### Ryan Walburn

During my junior year in high school, I was diagnosed with Hodgkin’s Stage 4B Lymphoma. Before I was diagnosed, I was having sinus issues that wouldn’t seem to stay away and was always wiped out during the day. After further examination and scans, the ENT doctor suggested that I go to the hospital to get some further scans which led me to Hersey Medical that night. The following day I was sent in for more tests and was diagnosed with Hodgkin’s. Before chemotherapy, I was sent into surgery to have tubing placed into my arm that was used to give me the chemo. A couple weeks into chemo the tubing was replaced by a port in my chest. After the chemotherapy I then received radiation treatment in my torso that lasted roughly two weeks.

While getting chemotherapy, I was able to live at home and traveled back and forth with my parents on the days of treatment. Each day consisted of an hour drive to the hospital, two to six hours of chemo, and then traveling back home. Thankfully during this my parents were able to drive me back and forth. My radiation days included going to the hospital, receiving radiation therapy that lasted about 30 minutes, and then going back home.

While receiving therapy I wasn’t able to move around a lot and mainly found entertainment through music. I’ve always loved music and was able to use it to help calm myself down. I was also able to keep my spirits up as my dad and I would listen to the comedy stations on the rides to and from the hospital. It was nice to be able to laugh and keep my mind off everything going on while we drove to the hospital and home.



*“Don’t be afraid to reach out to people if you are struggling.”*

- Marcus Josey,  
Cancer survivor



## Some Wonderful Tips From a Wonderful Local Organization



You may have seen the large, colorful quarterly publication from **Cool Kids Campaign**. We have a stack of them outside the door of the H.O.P.E. office and they are a great resource for kids and parents (and other family members). Devoted to “improving the quality

of life for pediatric oncology patients and their families by focusing on the academic, social, and emotional needs brought on by a cancer diagnosis,” the organizations is located in Towson, Maryland!

In addition to a fantastic website (<https://www.coolkidscampaign.org>), enthusiastic members, and a ton of activities, they also published a book titled “You Are Not Alone: Real Life Advice for Pediatric Oncology Families.” We have one copy of this excellent reference in our library available to check out. But much of the wisdom from the parents is too valuable not to share, so we’ve printed it below. Thank you, Cool Kids Campaign.

“Do not go online and start reading right away. Wait until you have all the information you need, then read for understanding, not for a prognosis or outcome.”

“There may be a time when your child seems fine to staff, but you know he or she is ‘off’ or you just have that feeling that something is not quite right. Speak up.”

“Ask the name and role of everyone who comes in the hospital room (or clinic) to talk to you.”

“Ask questions. Have your doctor and team break everything down for you so that you understand it on your level.”

“Accept gifts graciously, even if you don’t need another stuffed animal. Those who love you need healing also.”

“Steroids do strange things to our bodies. Aside from the never-ending hunger, they can affect personality.”

“It took four different combinations of medications to finally find the right blend that worked to minimize the nausea and sickness my son got with chemo.”

“Put must-have medical files on a USB in case of emergency. Carry a list of all meds and dosages.”

“Take time for memories.”

### Here are some helpful websites:

- |                   |               |
|-------------------|---------------|
| VolunteerSpot.com | MealTrain.com |
| CaringBridge.com  | Weebly.com    |
| CarePages.com     | Netflix.com   |
| GiveForward.com   | MomCology.org |
| Gamerosity.com    |               |

P.S. If you go to the website and click on Programs and scroll down to “You Are Not Alone,” you will find a way to receive a **free copy** of this marvelous book. And then check out the rest of the site if you haven’t already done so.

*Save the Date!*

### Ride for H.O.P.E. With the Twin Rose Lady Riders

Charity Ride With AMA Points

(2, 3, or 4 Wheels!)

Sunday, October 7

10—1:30

York Motorcycle Club

2333 Whiteford Road (next to the Galleria Mall)

For Information, contact Dawn, 717-471-7026, dmhtrlr@comcast.net



### Markets at Shrewsbury Helps H.O.P.E.

Saturday, September 15 – Visit us on the front porch!

All yard sale rental space fees are donated to H.O.P.E. for that day.



### Basket BINGO!!!!

Sunday, November 4

New Freedom Community Building

Doors open at 12:30; Games begin at 2.

Refreshments for sale by Tasteful Occasions.

Tickets \$15 before November 3; \$18 at the door.

25 games, 5 secret games, 1 thank-you game.

Call 717-227-2824.

Try **Kimmy's Café** at 106 Mill Street, Fawn Grove

Open Tuesday through Saturday 7 a.m.—8 p.m.

Sunday 8 a.m.—6 p.m.

- Features breakfast sandwiches and combos with all-you-can-eat breakfast buffet on weekends.
- Sandwiches, salads, subs, burgers, pizza, small plate appetizers for sharing, Italian entrees.
- BYOB or enjoy a beer from South County Brewing.

**Kimmy's will donate a percentage to H.O.P.E. and Triple Negative Breast Cancer Research during October.**

Be sure to get your raffle tickets for a cool Kimmy's Gift Basket.



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

Everyone is Welcome!  
(Cancer patients, care givers, families and friends)  
For more information  
Call 717-227-2824



*"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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