

H.O.P.E.  
President/Co-Founder

Barb Titanish

Assistant Director

Carol Nelson

Board of Directors

Craig Sharnetzka—Chair

Nicole Schmid-Vice Chair

Barb Spurlock—Secretary

Pat Grinnalds—Treasurer

Cheryl Schroeder

Ned Duke Jr.

Paula Thrasher

Abby Fry

H.O.P.E. Lifeline  
Production Volunteers

Jean Lillquist—Editor

Jo Huber

Kay Joy

Cindy Moran

Lynn Snook

Marty Streett

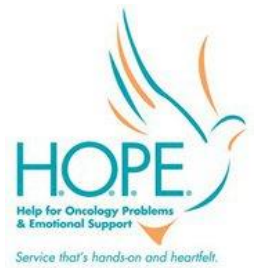
Maria Ellis

Jeannette Keech

Sandy Sharnetzka

Roxanne McKinney

# 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](mailto:barb@hopeforcancerfamilies.org) [www.hopeforcancerfamilies.org](http://www.hopeforcancerfamilies.org))

## Shrimp and Bull Roast

Saturday, October 5

7—11 p.m.



Jarrettsville Gardens,  
Jarrettsville Fire Hall

3825 Federal Hill Road  
Jarrettsville, MD 21084

All You Can Eat Buffet

Shrimp, Pit Beef, Pit Turkey,  
Pasta, Chicken, Sides

Beer and Wine

\*Silent Auction \* Door Prizes

\*DJ & Dancing!

## Annual Craft & Vendor Show

Saturday, October 19

8:30 a.m.—2 p.m.

Stewartstown Presbyterian  
Church



Local Crafters and Vendors

Lots of Holiday Gifts!

Chinese Auction, Raffle

Food Trucks

Admission: 2 Cans of Food for  
the Food Pantry

Interested in being a vendor?

Contact: 717-309-3824 or [bspurlock50@aol.com](mailto:bspurlock50@aol.com)

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 717-244-2174.

## Support Group

Date: Wednesday, Sept. 11

Time: 7:00 p.m.

Location: H.O.P.E. Haven

Topic: Everything

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

Physical Address:

13275 Blymire Hollow Rd.,  
Stewartstown, PA 17363

Mailing Address:

P.O. Box 279,  
Stewartstown, PA 17363

Phone: 717-244-2174

## INSIDE THIS ISSUE...

From the Editor's Desk	Pg. 2
Angel Corner	Pg. 2
Childhood Cancer Information	Pg. 3
One of Our 'Children'	Pg. 4
Online Support Groups	Pg. 5



*"Hope is a renewable energy source. Let it replenish your soul daily."*

*~ Alexandra Elle*

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

## FROM THE EDITOR'S DESK

It has been a great summer here at the HOPE Haven, with families enjoying their stay and kids having fun at the special **pool parties** and most recently the back-to-school pool and critter party, critters being snakes, turtles, rabbits, and a lizard. Parents were thrilled to see their kids having a last hurrah before hustling back to the classrooms. In fact, one father had as much fun as the kids as he organized games and entertainment.

Speaking of back to school, thanks to donations of back **packs and school supplies** and gift cards and money from our always generous friends, we made sure that 54 kids arrived the first day with all their required supplies. Marty, our Christmas elf, who doubles as the back-to-school supply superintendent, finds out what materials are required for students at various elementary and middle schools so that each child will be properly equipped and then sends letters to all our families with eligible children. Those who respond receive a packed back pack and gift cards for clothing. P.S. Thank you to the kids and parents who wrote us thank-you notes. You make all the difference.

As you can see, there is no such thing as summer doldrums at HOPE. If we're not preparing for an event or holding an event, we're attending or participating in events sponsored by other organizations. Barb attended a **golf tournament** at the end of July sponsored by **Wolfgang Candy**, in honor of a cherished former employee, Dave Simerly, who passed away from cancer last summer. Wolfgang donated \$5,000 to HOPE in honor of Dave. And just a few weeks later it was HOPE's turn to host our annual (16th) **Take a Swing at Cancer** golf tournament. The weather on Saturday, August 17 was perfect for our 102 golfers to have their usual fun on the links and enjoy prizes, food, and drinks.

Next month if you happen to be at the Haven you might hear the sounds of chainsaws and wood splitters. Thanks to all the donations of trees (many of which Barb's husband Ed and others have cut down themselves), nine volunteers are bringing wood splitting equipment and 30 others are coming to cut and stack. All of this so that you can buy cords of good wood for the winter. The day after that HOPE will be at the **Markets at Shrewsbury yard sale** where we are the beneficiary of the proceeds from the vendors' table rentals.

Don't forget to join H.O.P.E. for the Twin Rose Lady Riders, "Ride for HOPE" on September 21st, 2024. Sign up starts at 10am at Eisenhauser's HD, 100 Arensol Rd. Route 30 York.

Fall is around the corner, and with it hopefully fall weather. If you don't already have these on your calendar, add Saturday, October 5, for the **Shrimp & Bull Roast**, and Saturday, October 19, for the **Craft & Vendor Show**. See ads on front page for details.

The first day of school is exciting for students, as they reconnect with old friends and check out potential new ones. Will they like their teachers, will they know other kids in their classes, will their friends be on their lunch shift? Unfortunately, not every kid will experience this back-to-school excitement due to illness. September is **Childhood Cancer Awareness** month, and the National Cancer Institute predicts that an estimated 9,620 new cases of cancer will be diagnosed among children from birth to 14 years, and about 1,040 children are expected to die from the disease. Although cancer rates for this age group have declined by 70 percent from 1970 through 2020, cancer remains the leading cause of death from disease among children. On pages three and five of this newsletter we have more information about pediatric cancer, and on page four we have the story of one of HOPE's former patients, Shaylah Saylor.

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

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

August was a busy month with two golf tournaments. These tournaments are very work intensive and we need to Thank the organizers from Wolfgang's Be Blessed group who put on a wonderful event and donated half the proceeds to HOPE. We also would like to thank our dedicated Golf committee who pulled off another great event. Thank you, Ray Hasener for chairing this event and the rest of the committee, the Hooks, Andy Bobby, and my hubby Ed Titanish for all your work. As I said it was hectic time here at HOPE with help of 6 members from Drayer Physical Therapy Group, the Critter Guys, and all my awesome volunteers we hosted a back-to-school pool party where the kids had a great time.

---

# Childhood Cancer

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's 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. 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.

There are three groups of childhood cancers: leukemias and lymphomas, brain tumors, and solid tumors such as neuroblastoma. Leukemias are the most common childhood cancer. The two main types are acute lymphoblastic leukemia (ALL), and acute myeloid leukemia (AML). The first one is cancer in the child's blood and bone marrow; the second affects the blood cells and platelets.

Lymphomas are cancers in the child's lymphatic system. This is the group of organs, vessels, and tissues that protect us from infection and keep a healthy balance of fluids throughout the body. Lymphatic organs include the bone marrow, thymus, and lymph nodes. There are two lymphoma classes: Hodgkin lymphomas and non-Hodgkin lymphoma. The first is the most common cancer diagnosed in teenagers, but it may affect younger children. The second is more common in younger children.

Brain tumors are the second most common type of childhood cancer after leukemia. They can be benign (noncancerous) or malignant (cancerous). Most brain tumors in children start in the lower parts of the brain, such as the cerebellum or brain stem. They can cause headaches, nausea, vomiting, blurred or double vision, dizziness, seizures, trouble walking or handling objects, and other symptoms depending on the location of the tumor. Most childhood brain tumors are diagnosed and removed in surgery.

It must be stressed that unlike adult cancers, for example lung cancer, childhood cancers have no known causes. A few environmental factors, such as radiation exposure, have been linked with some types, and studies have suggested that some parental exposures (such as smoking) might increase a child's risk of certain cancers, but more studies are needed to explore these possible links. In recent years, scientists have begun to understand how certain changes in the DNA inside our cells can cause them to become cancer cells. DNA is the chemical that makes up our genes, which control nearly everything our cells do. Some children inherit DNA changes (mutations) from a parent that increase their risk of certain types of cancer. But most childhood cancers are not caused by inherited DNA changes. They are the result of DNA changes that happen early in the child's life, sometimes even before birth.

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 check-ups, 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**

# Shayla Saylor: A Two-Time Cancer Survivor

## By Age 20

Childhood cancer is a misnomer; once a child gets that diagnosis he or she is almost never truly healthy again. Because of the treatment they had as kids, by the time they're in their 30s or 40s, more than 95% of childhood cancer survivors will have chronic health problems, and 80% will have severe or life-threatening conditions. These 'late effects,' depending on the type of cancer and treatment(s), can include learning problems, abnormal bone growth, thyroid problems, hearing loss, vision problems, heart problems, organ damage, neuropathy, and an increased risk of future cancers.

Barb has often said that her most heartbreaking patients are the children; her first pediatric case was a baby who was diagnosed with cancer at three weeks of age. (He survived, and Barb has stayed in touch with him.) Fifteen years ago, one of HOPE's childhood cancer patients was a pre-teen named Shaylah Saylor. Shay was 11 when she was diagnosed with anaplastic large cell T-cell (ALCL) lymphoma in February 2009. It is a rare type of non-Hodgkin's and usually presents in older age groups and more likely men; it is rare in children.

Because of this, and because what Shay first noticed was a lump in her breast, doctors declared the problem was related to hormones and she was too young to have breast cancer. Not satisfied with two doctors' dismissals, Shay's mother took her to a third who removed the lump and then discovered more lumps in her lymph nodes. The doctor concluded it was not breast cancer but a rare (for children) type of lymphoma which actually attacks the spinal regions first.

Treatment at Hershey quickly followed. The regimen was seven different chemotherapies seven days a week, followed by a week off, and then the chemo again. This treatment lasted from late February to the end of August. Each Monday the treatment was preceded by a spinal tap. After all was said and done, Shay had had more than 52 lumbar punctures (spinal taps). Of course the treatments didn't come without side effects. Shay had to stay at the hospital the entire time because they discovered she had a blood clotting disorder; in addition to that she experienced back problems and anemia which required blood transfusions. Shay spent half of grades five and six being 'home-schooled' at Hershey.

Junior high brought a return to a somewhat normal life. Despite back pain and neuropathy, Shay excelled in classes and threw her all into music, singing in her school's show choir, chorus, madrigals, and musicals. She also played an important role in Penn State's mini-thon at her school to raise money for the Four Diamonds at Penn State Children's Hospital.

### *Four Years of 'Normal' Health Later...*

In the beginning of her junior year Shay began gaining weight, and no amount of calorie counting or exercise could counter it. At the same time her throat began hurting and at times actually felt as if it were closing up. When she felt a lump she saw a doctor who took different samples of her thyroid and discovered that cancer covered her thyroid and the front of her throat. Surgery removed her thyroid and 19 lymph nodes in the region. Shay was then treated with radioactive iodine and had to be isolated during that time. For the remainder of her junior year and her senior year Shay finished school by means of an alternative program and didn't graduate with her classmates.

In spite of all her health problems, Shay applied and was accepted to college. After two years she found that attending classes and keeping up with assignments while at the same time working to pay her tuition was more than her body could handle, so school was put to the side temporarily. And then when she was 25 the impossible happened: Shay became pregnant, after being told it could never happen because of all the chemo drugs put into her body. Her body concurred with that conclusion, and as Shay said, treated her baby as if it was a parasite. Shay lost 50 pounds during that pregnancy and her blood clotted so that she had to be put on blood thinners. Delivery was difficult, but her baby girl was born healthy and at a year is walking and saying words. Another amazing thing happened a little over a year after her baby was born: Shay became pregnant again. This time she 'only' lost 35 pounds, but the pregnancy was so difficult that her second little girl had to be delivered early.

Both girls are healthy and keep Shay and their father on their toes. Neuropathy, back pain, and arthritis are still part of her daily life, but Shay's upbeat optimism (and wry sense of humor) allow her to keep those problems in the back of her mind and focus on enjoying her family and planning for the future (with no more children).

# Cancer Support is at Your Fingertips in the 21st Century

September has been designated as Childhood Cancer month. How ironic that this is also the month that kids go back to school. Unfortunately thousands of kids will miss school this year due to childhood cancer. These children would like nothing more than to be joining their friends and classmates instead of spending their time in hospital beds.

For parents of these kids, it's even harder. All parents would gladly take their child's pain and illness onto themselves. No book or doctor could have prepared them for this. However, in our technological world, pediatric cancer websites and Facebook pages are great places to go for information, resources, support, and friendship. Here are a few:

## American Childhood Cancer Organization (ACCO)

Begun in 1970 by a dedicated, determined group of parents of children with cancer, who originally called their group the Candlelighters, the American Childhood Cancer Organization now has over 100,000 families in its network and has spawned international organizations. According to its mission statement, ACCO is *"the oldest and largest grassroots childhood cancer organization in the U.S. and the only U.S. member of Childhood Cancer International. We are dedicated to making childhood cancer a national health priority through shaping policy, supporting research, raising awareness, and providing educational resources and innovative programs to children with cancer, survivors, and their families."* Check out the pulldown menu item "Get Help" for a resources, local groups, 24-hour online peer support, and even financial assistance. <https://www.acco.org/websites-for-kids-with-cancer/>

## Four-Square Clobbers Cancer

Another valuable internet site for childhood cancer is Four-Square Clobbers Cancer <https://4sqclobberscancer.com/what-are-we-doing/>, helped into existence by The Nicholas Conor Institute and edited by Joe Baber, a volunteer for TCNI. 4Square is a 'conversational blog that is dedicated to improving the outcomes of children, adolescents, and young adults who are being treated or have been treated for cancer. The blog posts are written by a variety of people who have a common connection – someone with childhood cancer. They cover the political aspects of funding and other research problems, but there are also blog posts with such titles as "Father, Daughter Date Night," "Bereavement Meeting," "Jace Ward's Friends Can't Wait," "A 10-Year-Old, Speaking From Experience," and many more.

## Facebook Pages

### The Nicholas Conor Institute

A public site nonprofit organization with 6.6 million followers. "The Nicholas Conor Institute aims to bridge the gaps between academia and applied clinical practice to benefit children with cancer. This is one of Barb's 'go-to' sites for its total coverage of all aspects of childhood cancer.

### Pediatric Brain Tumor Foundation

A public non-profit site that has 32,000 followers. It leads the way in funding childhood brain cancer research to cure the kids, supports families affected by this disease, and advocates for policies that help patients, survivors and their loved ones.

### Cancer Caregivers Support Group

A public site that has six million members. About: "A place to show support for all the amazing caregivers of people with this horrible cancer disease. A place to vent and discuss critical issues facing all of us dealing with caring for a loved one with cancer and the loss of a loved one due to cancer." Here is a typical question posted on this site: "My husband was recently diagnosed with pancreatic cancer. We start chemo tomorrow. The cancer doesn't scare me as much as the side effects of the chemo. It was caught early and he is a surgical candidate. We just have a long road ahead. Any words of wisdom?"

### Stupid Cancer for Adolescents and Adults

A public group with 4.8 million members. "Stupid Cancer, a 501©3 nonprofit organization, is the leader in adolescent and young adult cancer advocacy, research, and support. We create shared experiences by producing life-changing live events and digital content that end isolation, build community, provide education, and foster meaningful relationships that last a lifetime. Our mission is to empower, support, and improve health outcomes for the young adult cancer community."

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.”*



RETURN SERVICE REQUESTED

H.O.P.E.  
Help for Oncology Problems & Emotional Support  
16580 Green Valley Court  
Stewartstown, PA 17363  
(717) 244-2174

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