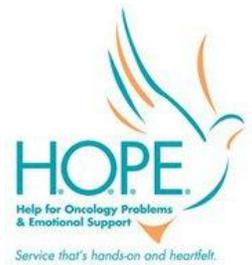


# H.O.P.E. LIFELINE



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

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.

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, September 21**  
 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,  
 Sides  
 Beer and Wine



**Silent Auction \*Door Prizes\*  
 DJ and Dancing**

## Annual Craft & Vendor Show

**Saturday, October 19**  
 8:30 a.m.—2 p.m.

New Freedom Community Building

50+ Crafters and Vendors  
 Lots of Holiday Gifts!

Chinese Auction, Raffle

Tasteful Occasions Fantastic Food  
 Admission: 2 Cans of Food for  
 the Food Pantry

Interested in being a vendor?

Contact: 717-309-3824 or  
 bspurlock50@aol.com

## Support Group Meeting

Date: Wednesday, September 10  
 Time: 6:30 p.m.  
 Location: H.O.P.E. Serenity Room  
 Topic: Lymphedema  
 Speaker: Susan Flohr, PTA  
 Wellspan Rehab Medicine

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## FROM THE EDITOR'S DESK

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, several pediatric cancer websites 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," "My Calling," "A 10 Year Old, Speaking From Experience," and many more.

### Imaginary Friend Society

Finally, a site created by the Pediatric Brain Tumor Foundation is Imaginary Friend Society (<https://www.imaginaryfriendsociety.com/about>). This site features short films for kids with the titles "Finding Out You Have Cancer," "Feeling Sad," "What is Cancer?," "What is an M.R.I?," "Blood Transfusions," "Radiation," "Chemotherapy," "Losing Your Hair," "Why Am I Tired All the Time?," "Who Is Taking Care of Me?," "Angry," and nine more.

### The Nicholas Conor Institute

Facebook page only. One of Barb's 'go-to' sites for its total coverage of all aspects of childhood cancer. See article on page 3 for more details.

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

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

The past month was a busy one! We would like to thank the Pleasant Home Regular Baptist Church of Airville for a wonderful day of fellowship and service at the HOPE Haven. A group of about 40 volunteers of all ages showed up and planted the butterfly garden at the Haven and in front of the soon to be offices.



At the Art and Music Fest everyone attending had a great time. We would love to thank the committee for all their hard work, the artists for their beautiful paintings, the musicians for lending their talent and all the wonderful volunteers.

FORE! The Golf Tournament was a great success! We would like to recognize the wonderful committee and volunteers for all their hard work. You couldn't ask for a better day, the weather was beautiful and the 124 golfers had a great time.

Thank you all for your commitment to H.O.P.E.!



### Wish list for kids with cancer:

- *Beat cancer*
- *Grow hair.*
- *Go to school.*
- *Get a puppy.*

- The Nicholas  
Conor Institute

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!

# Childhood Cancer Needs Your Help!

In 2005, 16-month-old Nicholas Conor was diagnosed with high-risk neuroblastoma. Unlike the parents of other children who are overwhelmed after receiving such a diagnosis, Conor's parents were cancer researchers who understood his cancer and the available treatments. As his mother, Beth Anne Baber, says in a 2014 interview on her website The Research Acceleration and Innovation Network (TRAIN), "Much like other solid cancers in children, the 'one-size-fits-all' treatment is chemotherapy at levels greater than what an adult would receive and in combinations that render most of the children with lifelong side effects and a decrease in life expectancy *if* the child survives. Histology concluded Conor's cancer was high-risk and aggressive. The recommended treatment was a standard-of-care bone marrow transplant. However, a limited number of biomarkers suggested otherwise. We chose a less intensive chemotherapy regimen over the recommended bone marrow transplant. Today, Conor is a healthy, active 10-year-old without any detectable side effects from his treatments."

How lucky their son was to have two knowledgeable parents. Most childhood cancer patients aren't so fortunate. Because of this, two years after their son's diagnosis Conor's parents founded the Nicholas Conor Institute, whose mission is "To accelerate the development of promising discoveries into targeted cancer treatments and deploy them in clinics worldwide for children, adolescents, and young adults." You can find this on facebook by typing the name in at the top of your facebook page. It's a wonderful site with a multitude of information and facts about childhood cancer.

Childhood cancers and adult cancers are not the same. Kids do not get breast, prostate, lung cancers, and adults do not get neuroblastoma, D.I.P.G., medulloblastoma, ewing sarcoma and other odd sounding cancers. Many of the adult drugs now being used for children cause late-term side effects, and the after-treatment effects of childhood cancer most likely will last a lifetime. Today's chemo kill cancer cells which are the fastest growing cells in an adult's body. In contrast, *all cells* in a child's body are fast growing cells. Unfortunately, because of lack of development, we are using adult chemo and radiation and both cause long-term side effects for childhood cancer survivors. "Curing" kids of cancer means a lifetime of fighting late and toxic side effects for more than 80% of the survivors. While adults have hundreds of drugs, only four drugs have been approved specifically for childhood cancers, and another 30 drugs, originally approved for use in adults, have also been approved to be used to treat cancer in children.

The majority of promising discoveries do not get into the development pipeline. They get stuck in the gap between discovery of the cure and clinical trials. This gap, known as the Valley of Death, is where the discovery should receive funding and technical support. According to the St. Baldrick's Foundation, "a [worldwide] volunteer-and-donor-powered charity committed to supporting the most promising research to find cures for childhood cancers and give survivors long and healthy lives," only 4% of U.S. federal funding is solely dedicated to childhood cancer research. About 60% of all funding for drug development in adult cancers comes from pharmaceutical companies, but for kids, almost none, because childhood cancer drugs are not profitable.

Four Square Clobbers Cancer (see Editor's Desk description) devotes much of its attention to the politics of funding pediatric cancer research and treatment. In fact, one pull-down menu category is "Get Involved." Currently they are asking readers to contact their Senators to urge them to support bills funding the National Institutes of Health, the National Cancer Institute, the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act, and the President's Childhood Cancer Data Initiative. Here's how you can do this:

- Send an email to Senators Casey and Toomey.  
     Senator Robert Casey <https://www.casey.senate.gov/contact>  
     Senator Pat Toomey, <https://www.toomey.senate.gov/?p=contact>
- It will take just a couple minutes to provide information to each man (name, address, telephone number, email address).
- After completing that, in the pull-down subject line of your email click on "Budget."
- Below this in the message box, type the following:

I am asking you to fully fund the House version of the 2020 budget for: The National Institutes of Health (NIH) at \$41.1 billion, NCI at \$6.44 billion; the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act, at \$30 million, and the President's Childhood Cancer Data Initiative at \$50 million. Thank you.

## Did You Know...

- The average child who is stolen by cancer will miss 71 birthday celebrations.
- 274 children will die from childhood cancer worldwide every single day.
- Childhood cancer wipes out 11 million years of human potential (life years) each year.
- Every day a busload of kids gets cancer. 365 busloads a years. 15,695 kids will get cancer in the U.S.
- Nearly one half of the boys who survive childhood cancer will grow up to have fertility problems due to the chemo and radiation treatment they received. Scientists have been working to find ways to correct this.

(Information courtesy of The Nicholas Conor Institute)

## Prostate Cancer, More Survivable Than Others, But Still Deadly

Prostate cancer is the most common non-skin cancer in America. One out of every nine men will be diagnosed with prostate cancer in his lifetime. In most men, prostate cancer isn't likely to kill them before something else does, but it still kills about 30,000 men a year. The five-year survival rate for most men with local or regional prostate cancer is nearly 100%. For men diagnosed with prostate cancer that has spread to other parts of the body, the five-year survival rate is 30%. Unfortunately, there usually aren't any early warning signs for this cancer. In rare cases, such symptoms might be cause for a man to contact his doctor for an evaluation:

- A need to urinate frequently, especially at night
- Difficulty starting or holding back urination
- Weak or interrupted flow of urine
- Painful or burning urination
- Difficulty in having an erection
- Painful ejaculation
- Blood in the urine or semen
- Pressure or pain in the rectum
- Pain or stiffness in the lower back, hips, pelvis, or thighs

There could be other causes for the above, and in fact, Prostatitis, or BPH (Benign Prostatic Hypertrophy, also known as enlargement of the prostate), are benign, more common diseases and can cause similar symptoms.

### Screening

The debate continues over when and whether to routinely screen. This is partly because of the uniquely slow-moving nature of most cases of prostate cancer. It is actually possible to live out a healthy life while you have prostate cancer that is not being treated (termed active surveillance); my father-in-law did. But some prostate cancer cases present an immediate threat, and need to be treated. When to start screening is generally based on individual risk. In men with no unusual prostate-related symptoms the following is recommended by the US Preventative Services Task Force as of 2017:

- 40 If there is a family history
- 45 If African American
- 50 No family history and not African American
- 55-59 Discuss with doctor
- Over 70 Screening is not recommended

### Risk Factors

There are a number of risk factors for prostate cancer, including racial background (African American men are 76% more likely to develop prostate cancer), geographical location (men who live north of 40 degrees latitude, north of Philadelphia, Columbus, Ohio, and Provo, Utah, have the highest risk for dying from prostate cancer of any men in the US due to a reduction in vitamin D levels from inadequate winter sunlight) family history, and age. Additional factors like smoking, a diet high in fat and processed carbohydrates, and consumption of too much calcium, seem to factor into more aggressive cases of prostate cancer.

### Prevention

What can you do to help prevent the disease? Many of the suggestions apply to warding off any types of cancer and are recommendations for a healthy lifestyle in general. Eat fewer calories and exercise more, try to minimize your consumption of red meat and dairy products, eat more fish, particularly those rich in omega-3 fatty acids such as salmon, mackerel, herring, lake trout, sardines, and albacore tuna. Avoid trans fatty acids (found in margarine). Try to incorporate tomatoes that are cooked in olive oil and cruciferous vegetables like broccoli and cauliflower. Avoid smoking, and drink alcohol in moderation. Also, avoid over-the-counter 'megavitamins.' If you follow a healthy diet with lots of fruits, vegetables, whole grains, fish, and healthy oils you shouldn't need any artificial supplements. But remember, if you are age 50 or over, if you are age 40 or over and African American, or have a family history of prostate cancer, you should consider a yearly rectal examination and PSA test, and you should discuss the risks and benefits of these screening procedures with your doctor.

### And This...

We are not here to ever give medical advice. Our purpose is to attempt to inform and to provide other areas that our readers may explore. It is always up to you and your medical teams to make the most informed health decisions. In the UK an online tool has been devised called Predict Prostate. It is "an individualized prognostic model for men newly diagnosed with non-metastatic prostate cancer." The patient enters details about himself and his cancer and then selects 'conservative management' or 'radical treatment' to see estimates of survival with each. For more information about this, go to <https://prostate.predict.nhs.uk>.

## Fighting Fatigue

Hand-in-hand with cancer-related pain is fatigue caused by cancer and treatment. This can feel like physical, emotional, mental exhaustion that goes on for a long time. This type of fatigue is not the same as feeling tired after not getting enough rest. Most people receiving cancer treatment have fatigue; some may have it for months or years after finishing treatment. Several factors may cause or worsen your fatigue.

- **Pain.** Living with constant pain is exhausting. What's more, many pain medicines cause drowsiness and fatigue.
- **Depression, anxiety, and stress.** These conditions can increase exhaustion. Managing stress and treating depression and anxiety often reduces fatigue.
- **Insomnia.** Stress, pain, and worry may contribute to insomnia, and medicines can also disturb normal sleep patterns.
- **Anemia.** Many people with cancer have anemia, which is when the red blood cell count is low. Treatment for this may include nutritional supplements, drugs, or blood transfusion.
- **Poor nutrition.** You may not be eating enough or eating the right foods.
- **Treatment side effects.** Certain types of treatment can cause fatigue. People commonly experience fatigue a few days after chemotherapy, a few weeks after starting radiation therapy, and after immunotherapy.

There are many strategies you can employ to minimize or help cope with fatigue, both in your day-to-day living and diet.

- Plan ahead and organize your work.
- Delegate tasks when needed.
- Schedule rests. Rest before you become fatigued.
- Pace yourself. Alternate sitting and standing.
- Identify effects of your environment: avoid temperature extremes; eliminate smoke or harmful fumes; avoid long, hot showers or baths.
- Prioritize your activities.
- Eat right. This includes plenty of protein, which rebuilds and repairs damaged body tissue. Drink plenty of fluids – a minimum of 8 cups of fluid per day will help prevent dehydration. Make sure you're getting enough vitamins. Try to consult with a dietitian.
- Engage in regular, moderate exercise as much as possible. This will help you stay active, increase your energy, and ward off tiredness and lack of energy and depression. Activities that carry little risk of injury and benefit the entire body include swimming, brisk walking, yoga, stationary cycling, and low impact aerobics (taught by a certified instructor). Some people also benefit from working with a physical therapist.

### Attention Friends

We know many of you are as excited as we are for our new Hope Haven. However, it is still a work in progress, and therefore we ask that people please refrain from stopping by while construction is still going on. Our insurer will not cover anyone who is not an employee.

Please wait for an official open house, which we will be announcing shortly. Thank you!

Also, for the next couple of months we ask the same for the office. We are starting to pack and still take care of our patients. We need to devote our time to our scheduled patients and still get done what we need to get completed for the BIG MOVE. We find ourselves being pulled in different directions and sometimes are not in the office. Please make sure you call and set up an appointment before stopping by the office. Again Thank you!

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 6

10—1:30



York Motorcycle Club

2333 Whiteford Road (next to the Galleria Mall)

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

## Buy A Brick

Brick Sizes

4 x 8 \$100      8 x 8 \$250

12 x 12 \$1000    24 x 24 \$2500

PLEASE VISIT

[WWW.HOPELIFELINE.ORG/BUYABRICK](http://WWW.HOPELIFELINE.ORG/BUYABRICK)

TO DOWNLOAD YOUR APPLICATION  
OR ORDER ONLINE VIA PAYPAL

Engraved commemorative bricks  
will be laid around our  
"Vacation from Cancer Retreat"

For more information  
Call the office 717-227-2824 or  
assistant@hopeforcancerfamilies.org

Help  
H.O.P.E.

Support  
H.O.P.E. Haven

Deadline December 31, 2019



**Fall Basket Bingo!**

Sunday, November 3

New Freedom Community Center

Tickets on sale at the office!

**Murder Mystery Dinner Theater**

Saturday, November 16

**Pine Ridge Farm**

Blue Ball Road \* Stewartstown

(More details later)

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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