Friend for Life Cancer Support Network

2024 Volume 32

Friend for Life News

Celebrating a Legacy



Judy Sisk [pictured at left], recalled our humble beginnings with founders Phil Bramblette and Chuck Sandmann in her keynote speech at *An Evening with Friends* 2023: Celebrating 35 Years

"Mr. Rogers was always reminding us to look for the helpers and I see a roomful.

"In 1988 U.S. first class postage rates were raised to 25 cents and post cards to 15 cents; gasoline was \$1.13/gallon; the 1988 NCAA winner was Kansas; the Kentucky Derby

winner was Winning Colors...a filly!

"In 1988, Taxol had positive reports from a Phase II clinical trial for activity in ovarian cancer. Most chemotherapy was still given in the hospital.

"In 1986 the first national cancer survivorship meeting was held in Albuquerque New Mexico. In conjunction with Catherine Logan, they laid the foundation for National Cancer Coalition for Cancer Survivorship.

"One of my first educational statements to patients and their families was that they were survivors in the next moment after diagnosis.

"Two persistent and tenacious dreamers met after voicing a frustration in getting information for "just how to live in spite of a cancer diagnosis. Not content to be a patient patient, these two remarkable men tackled identifying information sources and communication with like-minded groups across the US.... well before cell phones and mass media outlets.

"Our first introduction to the team they formed was when the three of us met at a Hardees. At that time Hardees' slogan was 'We're out to win you over". The new food item was a breakfast biscuit called The Rise and Shine Biscuit. That name was representative of this dynamic duo. [cont page 2]



FRIEND FOR LIFE CANCER SUPPORT NETWORK

OUR MISSION

To help persons diagnosed with cancer and their loved ones navigate the path through diagnosis, treatment and recovery by pairing them with a trained survivor of a similar experience so they can face cancer with someone who's been there.



Contact us:

•<u>staff@friend4life.org</u> (502) 893-0643 Phone (866) friend-4 Toll-free www.friend4life.org

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Celebrating a Legacy, continued

"Looking back at how quickly the FFL group evolved can make one's head spin. The unbridled enthusiasm of Phil coupled with the diplomatic approach of Chuck moved this group from a few interested individuals to a collective of like-minded community representatives. Initially we sought to have no medical system affiliation as we wanted healthcare providers to recognize our inherent worth...not shy away from a referral due to any particular affiliation. A board evolved and training sessions were developed for volunteers. And here we are 35 years later! We have moved from a soup supper in the home of the Steiners to this wonderful setting.

"Recognition must go to the families of these men. Wives and children had already lost precious family time to therapy and recovery days. I was never aware that the time and energy these men spent on developing this dream was ever seen as a negative in their recovery. In fact, it seemed to energize them through various low points.

"As a professional, this organization has provided a resource for my patients when their ears were numb from medical jargon. At a point there has to be the opportunity to understand that there is life on the other side of a cancer diagnosis. Quite simply, folks want to talk with someone who has been there.

"Our personal journey with survivorship began in June of this year with my husband's cancer diagnosis. Once there was a treatment plan established, the next step was to recognize there was a fellow survivor at the ready. It was comforting to know that peer support was a pillar at the ready."

~ Judy Hubbs Sisk

"My mission in life is not merely to survive, but to thrive; and to do so with some passion, some compassion, some humor, and some style." ~ Maya Angelou



Co-founders Chuck Sandmann (I) and Phil Bramblette (r)

Providing the Patient and Caregiver Voice in Research

"CONGRATULATIONS on 35 years of changing lives! Indeed – of improving lives for individuals and countless families! It is absolutely amazing to think of all the lives you have touched and changed, along with the many there who serve with your Friend for Life Cancer Support Network. Plus, all those who have worked with your organization over the years – and special kudos to those with the vision to begin Friend for Life 35 years ago. What a wonderful time to celebrate! It sounds like this will be a lovely celebration with many there.

"I wish to send our appreciation for each of you, along with the many others who have worked with Friend for Life throughout these 35 years since the network began. What an amazing, giving, healing history. On behalf of myself, Elena Joos, Melissa Flathmann, Angeline Herrick, and Jill Addai - my coworkers and I greatly appreciate your support for the research programs, too, as you have nominated tremendous individuals to serve as consumer reviewers! **This means SO much to us as your nominees truly DO represent the voice of communities affected by breast, ovarian, kidney, pancreatic, prostate and many other cancers.** We are always amazed how well you know so many tremendous people. The review they provide for the Impact the research would have - is invaluable.

"Thanks for each one of your nominations over the years who served with the Congressionally Directed Medical Research Programs (CDMRP), and ALL they bring to the scientific peer review process! It is transforming lives, too. A special thanks for all the wonderful day-to -day work you all do! It is appreciated, commended, and celebrated!!! We are so glad to hear you will have an occasion to celebrate your 35th Anniversary together in August. You truly do live your mission – empowering people to face cancer, with someone who's been there! It is empowering in countless ways, as you well know! With our thanks and heartfelt appreciation!"

Amy Klimas, Consumer Reviewer Administrator, Sr. Peer Review and Science Management

"The <u>Congressionally Directed Medical Research Programs</u> (CDMRP) welcomes patients, survivors, family members, and advocates to play a pivotal role in the future of biomedical research funding.... By integrating patients, survivors, family members and/or care takers into the scientific review process, the CDMRP is able to enrich the scientific review with personal perspective, passion, and a sense of urgency that ensures the human dimension is incorporated in the research focus. Over 2,000 consumers have served as Peer and Programmatic reviewers since 1995. By partnering with consumers, the CDMRP strives to find and fund collaborative research that discovers, develops, and delivers health care solutions for Service members, Veterans, and the America public."

To date, 25 Friend for Life volunteers have participated as Consumer Reviewers with this program.

Reaching Rural: Friend for Life in Eastern Kentucky

Friend for Life Cancer Support Network recently received funding from <u>Gilead Sciences</u> and <u>Pfizer</u> to increase outreach and provision of peer support to Eastern/Appalachian Kentucky, thanks to the grant-writing skills of **Shelly Wyman**, FFL Peer Navigator.

"Nationally, Kentucky ranks first in all-site cancer incidence and mortality, partly because of the high rates of cancer in its eastern 54-county Appalachian region as compared with the non-Appalachian counties in central and western Kentucky."

"Kentucky's high rates of cancer are attributed to disparities in socioeconomic status, exposure to environmental factors, limited access to health care, geographic isolation, lower rates of health literacy, and at-risk health behaviors such as tobacco use."

~ A Social-Ecological Review of Cancer Disparities in Kentucky. Sharon Rodriguez, MHA, Nathan L. Vanderford, PhD, Bin Huang, DrPH, MS, and Robin Vanderpool, DrPH South Med J, National Library of Medicine

- ♦ There are currently 408 active Friend for Life Peer Navigators
- 60% of Friend for Life Peer Navigators reside in Kentucky, but only 5 live in an Appalachian county
- Friend for Life has received direct requests for support or interest in volunteering from 92 of Kentucky's 120 counties over the past few years; of these, 30 are Appalachian (out of 54)

Goals:

- Increase delivery of peer support to residents of Eastern Kentucky
- **O** Increase the number of Peer Navigators who reside in Eastern Kentucky
- Add a Board Member who resides in Eastern Kentucky
- Add Staff who resides in Eastern Kentucky

Activities so far...

- Had info table at MCCAN (Markey Cancer Center Affiliate Network) Annual conference 12/2023
- Met with MCCAN representatives throughout Eastern and Central Kentucky
- Sent FFL materials o Ashland, Lake Cumberland, Winchester, Georgetown, Morehead, UK/Markey
- Judy met with Jonathan Boggs, Appalachian Regional Healthcare about co-marketing, providing support services
- Virtual Clinical Conversations session with students from Pikeville College of Osteopathic Medicine and a panel of Peer Navigators Wednesday, February 7
- ♦ Lori Beth spoke with providers in Ashland, KY 2/29, Kings Daughters Medical Center
- Participated in Health Conference at St. Claire Regional Medical Center, 3/ 5
- Plans to participate in the MAMAW (Mountains of Appalachia Music, Arts and Wellness) Festival
 7/2024 in Harlan, KY

From the Staff of Friend for Life Cancer Support Network



Grandfather A.R. Kasey's first church, Columbia, KY

The 2024 Friend for Life Cancer Support Network Board of Directors

Kristen Mellinger, President Mary Dickman, Treasurer Bart Bushong, Governance Chair Brittany Cook Jason Howard Scott DeGaris Karen Donahue Jim Gaffney, MD Tara Gnau Amy Holthouser, MD Haleh Karimi Laura Mitchell Joan Scales Janell Seeger, MD Kenya Whitfield Connecting Friend for Life with Eastern Kentucky has long been a personal priority. Cancer rates in Appalachian Kentucky are often the highest in the nation. The easy-toaccess support that FFL provides has always seemed to me to be a perfect fit for residents of these counties. The landscapes are stunningly beautiful, but the mountains and hollers limit access to cancer care and supportive services.

Over the years, we've formed and strengthened relationships with providers that serve Eastern Kentucky. Receiving \$30,000 in grant funds means we are able to make real progress with this project at last.

What I wasn't expecting was a personal connection to Appalachian Kentucky. I recently attended a meeting in Harrodsburg, birthplace of Abraham Lincoln. I discovered that just south of Harrodsburg was the birthplace of my daddy, in Columbia Kentucky, in the Appalachian County of Adair.

I spent some time exploring Columbia and re-read my Grandfather Kasey's account of moving with his new bride to his first appointment as pastor of the Columbia Methodist Church, then welcoming a daughter and son.

I truly look forward to learning more from residents of Eastern Kentucky and working to

strengthen cancer support services in these communities which will, in turn, strengthen Friend for Life.



Judy Kasey-Houlette, Executive Director

Greetings from Lexington, my Friends – I trust this finds you well and eager for spring like me. Did you know in 2023 Friend for Life received over 1,200 inquiries? With just a few months into the new year, 2024 promises to be bright and notable. From a strategic and rewarding half-day retreat with our board members to early selection of a regional celebrity for our Annual Evening with Friends event (no, you won't hear it from me) to new partnerships as we expand our services to the east, rarely is there a dull moment.

I constantly meet amazing folks and colleagues with a heart dedicated to our cause. However, simply put, we wouldn't be here without you. Each of you have traveled a path that so uniquely equips you to make a difference for someone else...but it isn't just your personal journey, but also your compassion that distinguishes you...and for that we are incredibly grateful!

With the promise and newness of Spring, I trust you see the impact we are making together. The priority to serve more individuals and clinics, the rewarding opportunity to connect with a new friend or the nudge of a referral for a new peer navigator,

collectively, each and every effort has a rippling effect. As we continue to make strides daily, please keep us in mind if you need a FFL poster to hang in

your fellowship hall or a few informational rack cards to share within your community, club, or organization. Just drop me an email or give me a call, I look forward to hearing from you.

KMB

Lori Beth Miller, Assistant Director

Upcoming Events

Thursday, May 7: Kentucky Gives Day Saturday, August 24: An Evening with Friends 2024

May 15-17, Our friends at Reel Recovery are hosting a fly-fishing retreat for men affected by any form of cancer. The event will be at Lake Cumberland State Resort Park in Kentucky. Apply online: reelrecovery.org. For more information, call 800-699-4490 or email info@reelrecovery.org



An Evening with Friends 2023: Celebrating 35 Years

Friend for Life Cancer Support Network held another successful fundraiser last August, raising \$62,000! We could not have done this hybrid event without the amazing support of our Board of Directors, and technical/production wizardry provided by RFX Technologies. Thanks as well to Emcee Claudia Coffey, Auction Facilitator Ben Ruley, Keynote Speaker Judy Hubbs Sisk, Host Bart Bushong, VIP Hour Donors Mark and Barb Lechner, and extra kudos to Barb for the gorgeous baskets and floral arrangements.



Judy Kasey-Houlette & Judy Hubbs Sisk



Bobbie Daniels Award winner Diana Ernst with Judy & **Kristen Mellinger, Board President**



Joan Steiner Award winner Judy Kasey-Houlette, with Kristen & Bart Bushong, Board Member Emeritus

Apologies to 2023 awardees Joan Scales and Lee Cybulski whose photos were mis-labeled in our 2023 Newsletter.

In Grateful Remembrance









away since the publication of our last newsletter.



We treasure fond memories of these beloved volunteers who passed



Cathy White

Elizabeth Wayne

Mike Deal

Vera Marie Stuart

Sara O'Neil

Kyle Bianconcini

What We've Been Up To...

Friend for Life volunteers are cancer survivors and caregivers trained by healthcare professionals to prepare them to support others as they confront the emotional, psychological and practical uncertainties posed by cancer. We refer to our volunteers as Peer Navigators. Support seekers are matched with Peer Navigators by diagnosis, course of treatment and, to the extent possible, age and gender. No other organization in our region offers matched one-to-one support for all types of cancer. At the end of 2023, Peer Navigators numbered 408. They range in age at diagnosis from 6 to 84 and represent survival of a wide range of cancer types.

During 2023, Friend for Life Cancer Support Network:

- * Staff responded to 1,233 requests for support and matched 562 individuals.
- * Peer Navigators donated over 5,500 hours.
- Peer Navigators spoke with over 150 students and their faculty mentors at the University of Louisville School of Medicine and for the first time, students of Osteopathic Medicine in Pikeville, Kentucky. Peer Navigators have shared the cancer patient perspective with over 7,000 future healthcare practitioners since 2007.
- Staff partnered with other one-to-one cancer support organizations across the country in order to provide peer support for persons diagnosed with rare forms of cancer or recently developed treatments.

Friend for Life seeks to:

- provide cost-free peer support to persons diagnosed with cancer and to their loved ones.
- provide quality training and ongoing support and education to Peer Navigators.
- enhance outreach to minority and underserved populations, with special focus on Kentucky.
- reflect advances in cancer knowledge and treatment through ongoing recruitment of survivors who have benefited from these advances.





Our Fabulous Sponsors

















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Colors shown at right: blue, grey, red Sizes S through XXXL Order online: http://bidpal.net/ fflswag

Friend for Life volunteers get one tee FREE!Don't have one? Let us know!You can also order by calling or emailing us:staff@friend4life.org502.893.0643

On the back of the tee: "Facing cancer, with someone who's been there."

