



Patient Empowerment Network

2023 Impact Report



Welcome from Board Chair, Darla Brown

Dear Friends,

2023 marked a transformative year for the Patient Empowerment Network (PEN), ushering in a new chapter under the dynamic leadership of Tracy Rode as CEO & Executive Director. Tracy brings a wealth of non-profit leadership experience, deeply rooted in over 20 years of work with patients. Motivated by her own experience with thyroid cancer, she has truly embraced PEN's mission and we are all inspired by the new energy she has brought to the organization.

PEN remains committed to empowering cancer patients and their care circles with the knowledge, tools, and support necessary to navigate the healthcare system. This past year, we reached over 363,000 individuals, marking a significant milestone in our ongoing effort to ensure every person we serve has the best outcome possible.

In line with our organizational growth, I am delighted to welcome new talents to our team: Susan Liberatore as our Individual Giving Director, Nicole Normandin, LMSW, as our Marketing and External Affairs Director, and Joelys Gonzalez as Program Manager.

With heartfelt gratitude, I want to acknowledge my fellow board members who generously volunteer their time and resources: Nancy Gatschet, LaWanda Byrd, Alyssa Gutjahr, Lauri Bolton, Sujata Dutta, Andrea Marquez, and Eric Vicks. We are also privileged to welcome new members to our board:

- Deirdre McGinley-Gieser: Deirdre contributes deep expertise in cancer research and advocacy, honed over more than 25 years as a leader at the American Institute for Cancer Research (AICR).
- Pam Rattananont: Pam brings over 25 years of experience in addressing care coordination and accessibility challenges in high unmet medical need areas, such as cancer and rare diseases.

The varied expertise and experiences of our board members enriches our shared mission, amplifying our ability to make a meaningful impact on those navigating cancer.

Finally, a sincere thank you to our broader PEN community—our staff, volunteer empowerment leads, program volunteers, donors, and partners—for your dedication and the difference you make in the lives of those affected by cancer each day. Your dedication is the foundation upon which we build our future, aspiring to empower more individuals with every step we take.

Together, Onward for Greater Impact,
Darla Brown
Board Chair



A Message from Tracy Rode, Executive Director

What an honor it is to serve the cancer community at an organization as impactful as Patient Empowerment Network. It has been an incredible year for me, after becoming Executive Director in April 2023.

I could not be more grateful to my coworkers, Board of Directors and Empowerment Leads, who all welcomed me with their wisdom, generosity and openness. My heartfelt gratitude goes to Robin Barnes, who served as Interim Executive Director from July 2022 to April 2023, for her leadership, kindness and collaboration before and after I joined the team.

In creating this report, I hoped to not only provide outcomes from 2023, but to impart a true sense of the passion and commitment to excellence we bring to all of our efforts. Underpinning everything is science; all of our programs and content are evidence-based and carefully developed to provide the most return on investment of our time and the generosity of our donors and sponsors.

The last word of our name, “Network,” is so important when trying to understand what PEN is all about. Our network of collaborators and partners help multiply the effect of what each of us can achieve as individual organizations.

On the next pages, we share some of the biggest accomplishments of 2023. While it’s rewarding to look back at a year’s worth of results, the most important thing we did in 2023, and will ever do, is provide individuals impacted by cancer a sense of empowerment and a better understanding of what’s ahead.

2024 will be a building year for PEN as we:

- Expand our website to become a true resource portal. Our site users will be able to save information and receive curated content based on specific characteristics of their cancer journey, and most importantly, what they want to know. We’ll get site visitors to their desired content easily, whether they are an experienced “sleuth” or need a guide.
- Increase cancer types covered to 120 (from the current 23) and develop broad content that transcends cancer type, offering supportive, action-oriented, empowering learning.
- Finalize a new strategic plan with key performance indicators to guide our steps for the next three years
- Diversify revenue streams to help us create broad-reaching initiatives that cross cancer type and stage.
- Join our voice with other organizations in advocacy to shape public policy and ensure that cancer is a top priority for government agencies

“I wish I’d had PEN when I was first diagnosed in 2010. Feeling empowered to engage in shared decision-making with my medical team would have changed my journey in many ways.” – Tracy Rode

No matter how cancer has impacted you, it changed your life. Throughout our organization, using our experiences as survivors and care partners is the most joyous way to validate our shared experience and pay forward the lessons learned from our own cancer journeys. Be a part of how PEN empowers patients, care partners and health care professionals. Email me at tracy@powerfulpatients.org, and let’s get started.

THANK YOU FOR MAKING OUR IMPACT POSSIBLE

Thank you for being a part of our mission and growth. In 2023, we worked towards serving more people, providing more support, and offering more programs than ever before. We express our deepest gratitude to you, our community of supporters, who help make fulfilling our mission possible.

100+

CANCER
TYPES

43

PROGRAMS

363k

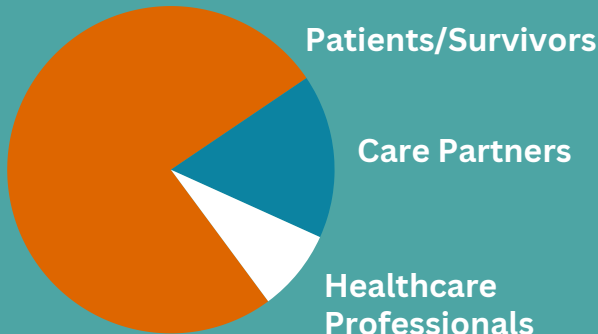
PARTICIPANTS

97

DOWNLOADABLE
RESOURCES

105

LANGUAGES



592

VIDEOS
PRODUCED

PROGRAM PARTICIPANT FEEDBACK

"PEN gave me the information I needed, when I needed it, in a way I could easily understand and share with family members."

"This program gave me a much better understanding of multiple myeloma, the mechanics of how it works and the many treatment options available. Your efforts toward improving patient knowledge and peace of mind are very much appreciated!"

Financials

PEN consolidated statement of financial position as of December 31, 2023.

ASSETS

Current and other assets	\$1,049,246
Investments	\$174,528
Property and equipment	\$514
TOTAL	\$1,224,288

LIABILITIES AND NET ASSETS

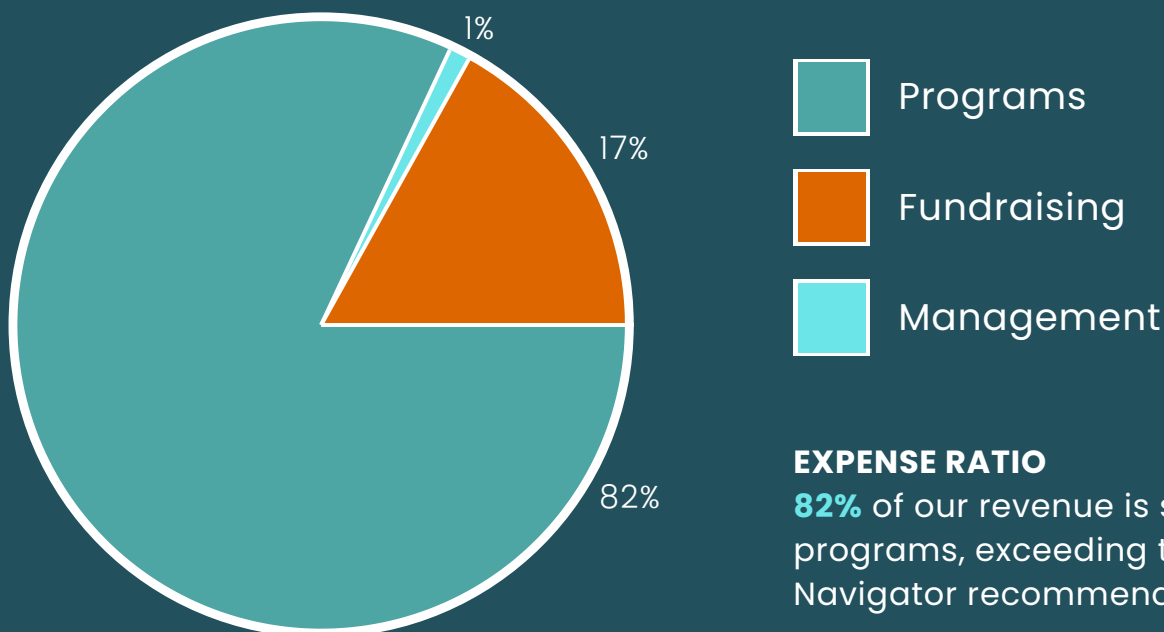
Current long-term liabilities*	\$368,944
Net assets	\$855,344

*Includes grant advances

AUDIT

To ensure transparency of how we use the donations we are so fortunate to receive, we opted to conduct a full voluntary audit of our 2022 finances. We are extremely proud of the results from our audit firm, Goff, Backa, Alfera & Company, LLC, of Pittsburgh, PA. To view PEN's complete 2023 financial statement, [please click here](#).

How We Spend Each Dollar



EXPENSE RATIO

82% of our revenue is spent on programs, exceeding the Charity Navigator recommended ratio of 75%.

Key 2023 Accomplishments

Fundraising and Operations

- Received a Google grant providing \$10,000 of targeted-search advertising at no cost to PEN
- Completed our first voluntary financial audit
- Launched peer-to-peer social media fundraising
- Conducted branding analysis with new mission, vision and values
- Integrated Salesforce and a new fundraising platform, GiveLively

Memberships

- American Psychosocial Oncology Society (APOS)
- American Society of Clinical Oncology (ASCO)
- Association of Community Cancer Centers (ACCC)
- Association of Oncology Social Work (AOSW)
- Cancer Alliance of Texas
- Cancer Patient Education Network (CPEN)
- CancerX (public-private partnership of the Cancer Moonshot)
- Chief
- Health Equity Acceleration Community of Practice
- Healthy People 2030
- National Association of Nonprofit Organizations and Executives (NANOE)
- National Council of Nonprofits
- Nonprofit Technology Enterprise Network (NTEN)
- Oncology Nursing Society (ONS)
- Philadelphia College of Osteopathic Medicine (PCOM)
- Tennessee Comprehensive Cancer Coalition
- Tennessee Oncology Practice Society

Partnerships

- Academy of Oncology Nurse Navigators (AONN)
- After Breast Cancer Diagnosis (ABCD)
- Alira Health/HealthStorylines
- American Cancer Society
- Cactus Cancer
- Cancer Hope Network
- Cure
- Endometrial Cancer Action Network for African-Americans (ECANA)
- Global Liver Institute
- Head and Neck Cancer Alliance
- Health Union
- HealthTree
- International Association for the Study of Lung Cancer (IASLC)
- Iowa Cancer Consortium
- Kidney Cancer Association (KCA)
- Leal Health

Participation

- American Society of Clinical Oncology (ASCO) Annual Meeting
- Psychosocial Oncology Professionals Symposium
- American Society for Hematology (ASH) Conference
- American Cancer Society Action Network TN Policy Forum
- United National Office of the Special Advisor's Academic Conference on Africa
- Industry
 - Amgen's Health Equity Summit
 - Incyte MPN Coalition
 - Incyte Working Group Shared Decision Making in DLBCL
 - Merck Bladder Cancer Patient Advocate Panel
 - Morphosys' MOR Community Connections series
- Medscape's "Elevating Health Equity"
- Future of Cancer Care Conference
- National Comprehensive Cancer Network's "Navigating the Care Continuum" Summit
- HLTH 2023 Conference
- Healthy People 2030 Champion, a project to set data-driven national objectives to improve health and well-being over the next decade, incorporating social determinants of health. It's a project of the US Department of Health and Human Services Office of Disease Prevention and Health Promotion.
- Living Beyond Breast Cancer
- Oatmeal Health
- Pancreatic Cancer Action Network
- Patient-Centered Outcomes Research Institute (PCORI)
- Patient Insight Institute
- Patient Point
- Patients Rising
- PeerVoice
- PlatformQ Health
- RMC Alliance
- Ryn Sloane
- Savor Health
- Throwing Bones
- Uplifting Athletes
- Virtue Research
- Worth the Wait

Staff



Tracy Rode
Executive
Director



Aicha Diallo
Senior Director
of Programs



Joelys Gonzalez
Program Manager



Susan Liberatore
Individual Giving
Director



Nykema Mpama
Outreach &
Engagement
Coordinator



Kara Rayburn
Digital
Communications &
Engagement Director



Nicole Normandin
Rueda, LMSW
Marketing & External
Affairs Director



Reagan Weist, MHA
Partnerships &
Programs Manager



Andrea Winchell
Development
Manager

Board of Directors



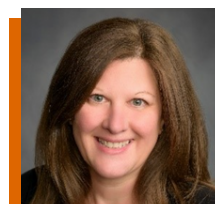
Darla Brown
Chair



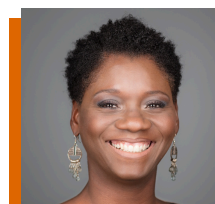
Alyssa Gutjahr
Secretary



Nancy Gatschet
Treasurer



Lauri Bolton



LaWanda Byrd



Sujata Dutta



Andrea Marquez



Deirdre
McGinley-Gieser



Pam Rattananont



Erick Vicks

Empowerment Leads

The Empowerment Lead program partners with our cancer community in an effort to join hands with patients, care partners, and support health communities to further enhance health literacy. This program is made up of highly passionate ambassadors volunteering from around the country, engaging with PEN's network of cancer patients and families, and serving as a direct conduit of empowerment.

Our strong team of compassionate volunteers does not give medical advice, instead, they help health communities adapt to the realities of living with a serious illness. PEN Empowerment Leads pay it forward as the communities' human bridge to survivorship as they understand first-hand the anxieties and uncertainties that come with a cancer diagnosis.



Jeff Bushnell



Sherea Cary



Jessica Catlin



Cora Connor



Art Flatau



Carly Flumer



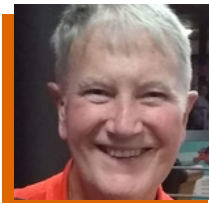
Summer Golden



Mikki Goodwin



Lisa Hatfield



Gary Hooker



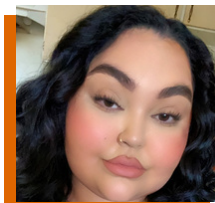
Mary Leer



Sabrina Ocasio



Linda Ryan



Sasha Tanori



Diahanna Vallentine



Volleen White



Christine Wu

Mission

Offer trusted information
to empower anyone
impacted by cancer.

Vision

Everyone has the
knowledge they need to
deal with cancer.

Values

We Are



Activators



Innovators



Collaborators

Who Work



With the
Upmost Integrity



To Champion
Equity

In August, our full staff team gathered in Nashville for branding and strategic messaging efforts with our facilitator, Carrie Collins of HOW. Our goal was to simplify our previously-lengthy mission statement, bringing it into alignment with our insistence on providing clear, understandable information.

To offer trusted information to anyone impacted by cancer: nine little words that speak volumes about PEN. We also created a vision statement for PEN: Everyone has the knowledge they need to deal with cancer. While it's a lofty concept, we work toward that vision every day.

Programs

Patient Empowerment Network's programs are evidence-based and driven by outcomes data to:



Help Patients

access clinical trials, understand biomarkers and testing, and access easy-to-understand, medically-vetted education from diagnosis through post-treatment/survivorship wellness



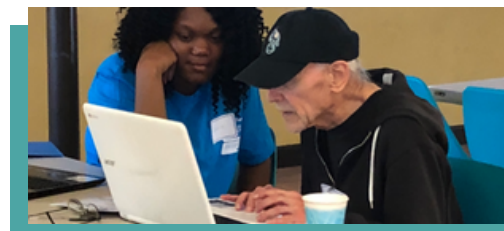
Assist Underrepresented Patients

to overcome barriers and bridge gaps in care by expanding reach within underrepresented areas and communities



Improve Digital Literacy

with online literacy training for the technologically inexperienced, both through partner organizations or direct to patient via self-paced training



Assist Care Partners

to help support, understand and participate in their patient's cancer treatment decisions



Improve Patient Communication

by sharing strategies with health care professionals to help them learn to better communicate with patients



Programs at a Glance

Early Detection and Testing

- DETECT – high risk individuals understand screening and testing
- INSIST! – patients and care partners understand biomarkers



Disease and Treatment Learning

- START HERE – customized program for newly diagnosed patients
- EVOLVE – education on clinical trials and new therapies
- ELEVATE – whole patient support for symptoms and side effects



Shared Decision Making

- [ACT]IVATED – bridging patient barriers to accessing care/gaps due to health inequities
- COLLABORATE – disease education resulting in actionable plan



Survivorship and Psychosocial Support

- INSPIRE – completing treatment and navigating the “new normal”
- RESTORE – wellness during and after treatment
- EMPOWERMENT LEADS – connection with real patients for evidence-based support



Special Audiences

- CARE PARTNER TOOLKIT – understand and participate in the patient’s journey
- EMPOWERING PROVIDERS TO EMPOWER PATIENTS (EPEP) – healthcare professionals learn patient communication strategies
- digital sherpa® and Digitally Empowered® – online technological literacy training and educational workshops



2023 Programs Update from Aicha Diallo, Senior Programs Director

In 2023, PEN's programs team spent a lot of time identifying key health disparities within cancer communities, by conducting needs assessments and creating health equity best practices to address the needs and wants of our patients and families through our programming. We proceeded by getting to know the audience we serve by listening to their priorities and including their voices at the center of everything we do.



Our strategies included capturing more demographics data and implementing long and short-term outcomes surveys to track the impact our programs have on the patients, care partners and health care professionals we serve. Our findings allowed us to shape the direction of our programs for 2024 and tailor them to reach more underrepresented communities by partnering with organizations on the local, national and international level.

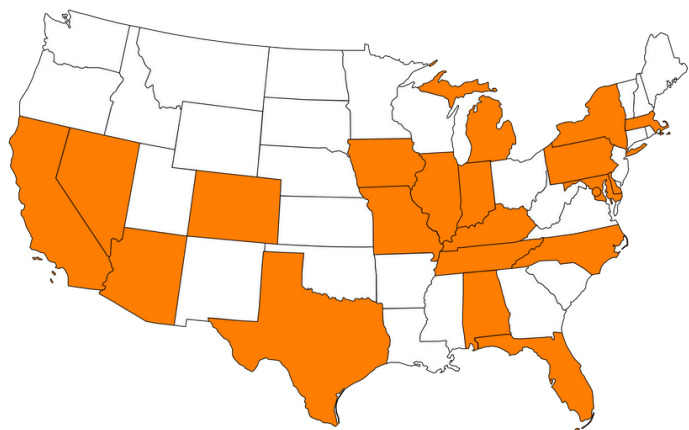
Through our surveys in 2023, we learned that our patients and care partners:

- Felt more confident and empowered to speak up about their care
- Felt comfortable taking the information they learned from the webinar and share it with their healthcare team
- Increased understanding of clinical trials and biomarker testing
- Felt more confident about getting a second opinion
- Enhanced knowledge of range of treatment options, managing side effects during treatment

They hoped that PEN would expand to include more cancer types, offer programs in languages other than English, and expand programming to topics such as survivorship and wellness/well-being. We listened.

- We are creating content for 120 additional cancer types
- Through a web content translation tool, you can experience powerfulpatients.org in over 100 languages
- Our programs Becoming Empowered, digital sherpa®, and Digitally Empowered® are available in Spanish.
- We are currently developing a robust suite of web content and program elements that cover supportive needs of patients and care partners, from side effects management to wellness after treatment.

Spotlight on digital sherpa® & Digitally Empowered®



Digitally Empowered® and digital sherpa® strive to enhance the technological literacy of cancer patients and their families, empowering them to access information and support throughout their journey with cancer.

Since its inception in 2016, both programs have reached almost 12,000 people impacted by cancer.

With the invaluable support of our partners, digital sherpa® and Digitally Empowered® have expanded their reach to over 20 states. Cancer Support Community DC had this to say about the program, “Members who received support from the digital sherpa® training will be better equipped to attend virtual support groups, communicate with their healthcare team using their portal/EMR, and use email more seamlessly to get program updates and group links. This has helped them receive and maintain peer support as well as connect more with providers.”

Looking ahead to 2024, we're excited to announce our plans for international expansion.

A Note on Health Equity

- We are dedicated to improving health literacy, equity, and treatment outcomes for all cancer patients.
- Health equity is the idea that everyone can achieve their best health outcomes regardless of who and where they are, acknowledging determinants of health that complicate care and influence outcomes.
- We acknowledge and address cultural considerations that impact the perceived or actual balance of power between patients and providers.
- PEN's greatest goal is to enable a patient to share in decision-making and have access to actionable, empowering steps to transcend barriers that affect access to care

Spotlight on Empowering Providers to Empower Patients

In addition to our broad variety of patient and care partner resources, PEN has also developed tools to help health care professionals empower patients to embrace a role in decision making. PEN's Empowering Providers to Empower Patients (EPEP) initiative:

- provides evidence-based tactics to improve physician-patient communication
- helps health care professionals connect patients in underrepresented communities with resources
- assists patients in overcoming barriers to accessing care and improving their cancer outcomes
- promotes the concept of cultural humility, which means entering into a relationship with the intention of learning about honoring the other person's beliefs, customs and values

In 2023, we continued to innovate EPEP by conducting interviews with 14 experts who shared invaluable insights on patient empowerment. We launched three specialized programs tailored to address the needs of individuals impacted by lung cancer, myeloproliferative neoplasms (MPNs), and multiple myeloma were recognized as Health Equity Heroes for our lung cancer EPEP resources.

91%

of participating healthcare professionals gained confidence to better facilitate shared decision-making with patients

91%

of participating healthcare professionals found relevant resources to share with their patients

21,337

healthcare professionals reached by EPEP in 2023

PROGRAM PARTICIPANT FEEDBACK

“

Thank you for this program. I'm a busy physician but want to always do right by my patients.

The webinar was amazing and provided great context to my colleagues and myself on cultural humility in the clinical trials space.

”



Patient
Empowerment
Network

powerfulpatients.org