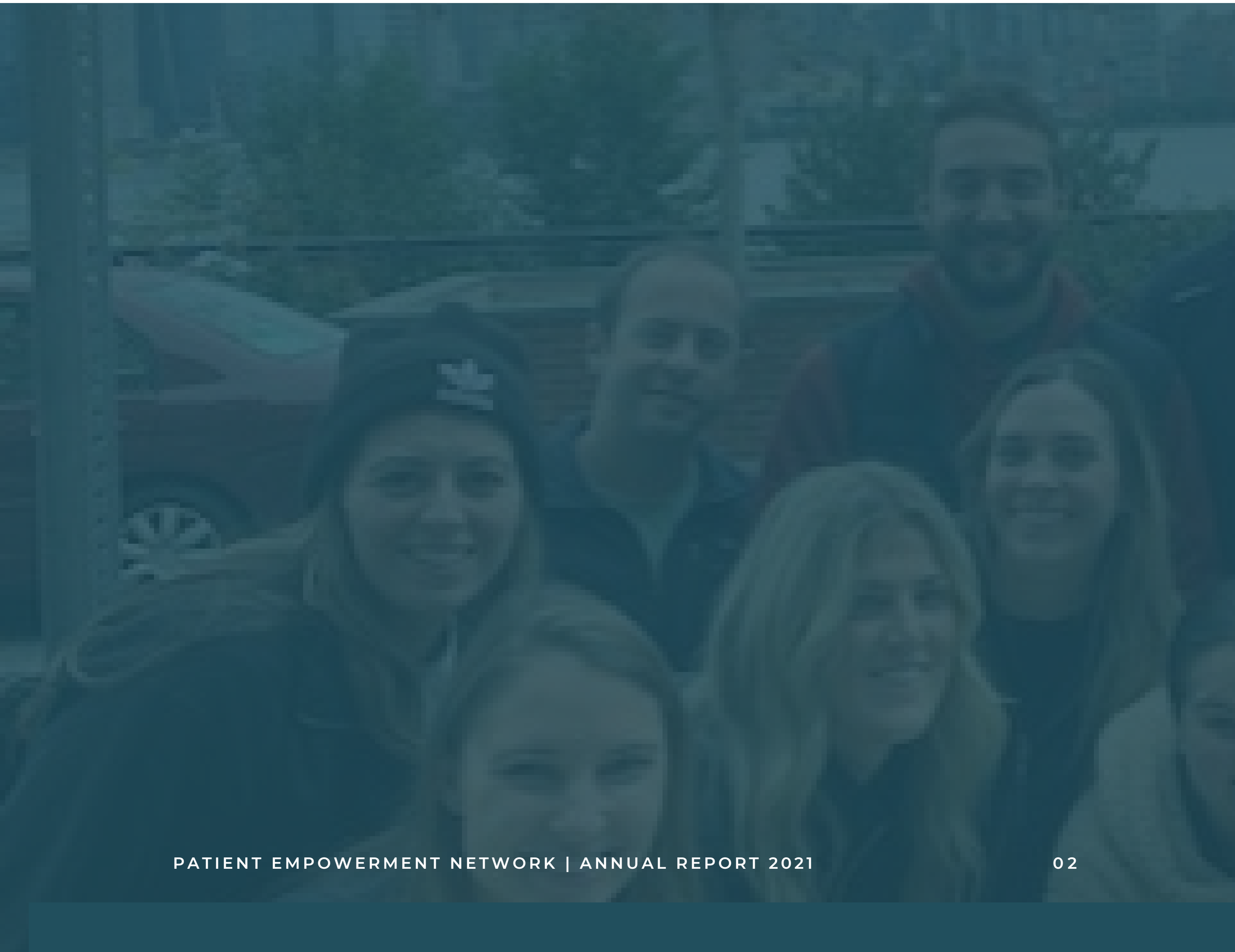
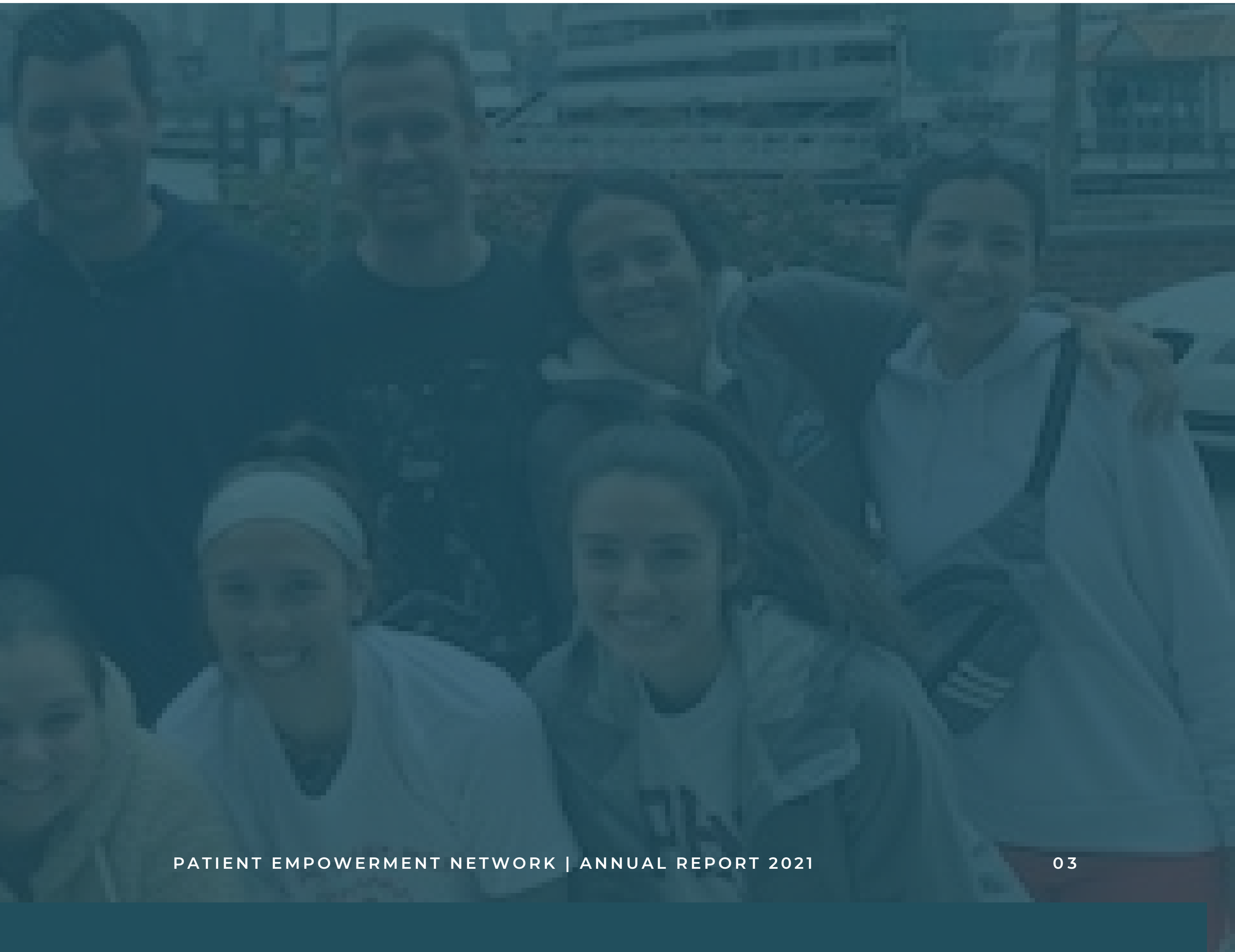
Patient
Empowerment
Network

# Annual Report

# 2021

# contents





# message from our board chair

Dear Friends,

As we enter our final year of our three-year Strategic Plan that we established in 2019 under Andrea Conners' leadership as Executive Director, I am pleased to report that the Patient Empowerment Network has already exceeded many of its strategic goals. This means that we are making more of an impact now than ever before as we strive to empower the patient journey, expand PEN's reach and increase its visibility, grow PEN's partnerships, and build new funding sources.

One area of growth that we are particularly proud to share is the expansion of our Path to Empowerment content into three additional cancer areas this past year to include colon, head & neck, and diffuse large B-cell lymphoma (DLBCL) cancers. That means that we now support cancer patients and care partners through 14 different cancer types! In 2022, we'll expand our programs even further into advanced bladder cancer, non-melanoma skin cancer, and two additional non-Hodgkin lymphoma subtype cancers: follicular lymphoma and Waldenstrom's.

In 2021, though we saw a 64% increase in the number of individual donors from the previous year, we experienced challenges in connecting with foundations. By introducing PEN to foundations in your network whose giving aligns with PEN's mission, you would be helping us to build relationships that will enable PEN make an even greater impact in the lives of cancer patients.

On behalf of the Board, I want to acknowledge the PEN staff and volunteers who make up our Patient Empowerment Network community: our Network Managers, program volunteers, donors, and partners. It is your dedication to PEN's mission that makes it a reality in the lives of people with cancer every day.

Thank you also to my fellow Board Members who generously volunteered their time and resources towards PEN's mission in 2021: Jack Aiello, Lawanda Byrd, Nancy Gatchet, Alyssa Gutjahr, Sajjad Iqbal, Ray Parisi, and Scott Riccio, and our General Counsel, Tom Pedreira. In October, we welcomed three new Board Members: Sujata Dutta, Andrea Marquez, and Eric Vicks. They bring a wealth of experience, passion, and knowledge to PEN's leadership team, and we have already benefited greatly from their presence.

We extend a special thanks to Scott Riccio, who became our first Board Member Emeritus in October, for his many years of service. Scott had served as PEN's Board Chair and President from 2017-2019 and subsequently as a Board Member. His leadership and dedication to PEN's mission continues to inspire us in innumerable ways.

In 2022, through your support, we will continue to give people the resources and knowledge they need to navigate the path of cancer so they can get the best care possible.

Sincerely,

Darla Brown

Darla Brown
Board Chair

> One area of growth that we are particularly proud to share is the expansion of our Path to Empowerment content into three additional cancer areas this past year.

# what's new in programs

In 2021, we introduced three new health networks and five new programs. We also welcomed three board members and five network managers.

## new health networks

01

### Colon Cancer

Colon cancer, sometimes called colorectal cancer, is the fourth most common cancer diagnosed the United States.

Program: The Pro-Active Colon Cancer Patient Toolkit

02

### Diffuse Large B-Cell Lymphoma (DLBCL)

Diffuse large B-cell lymphoma (DLBCL) is an aggressive type of Non-Hodgkin Lymphoma (NHL), which is one of the most common cancers in the United States.

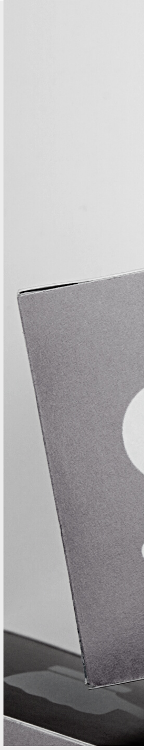
Program: The Pro-Active DLBCL Patient Toolkit

03

### Head & Neck Cancer

Head & neck cancers account for nearly 4% of all cancers in the US.

Program: Head & Neck Cancer TelemEDucation



# new programs

## 01

### digital sherpa™ Train-the-Trainer

Trains community-based organizations to offer digital literacy skills training workshops to their local cancer patients and care partners.

## 02

### What You Need to Know Before Choosing a Cancer Treatment

Explains how biomarker testing may impact prognosis and treatment decisions. Enables patients to get the best, most personalized cancer care.

## 03

### Engage

Encourages patients to play a more active role in their care.

## 04

### Patient-to-Patient Diverse Clinical Trial Profiles

Bridges the gap between patients who have participated in clinical trials and those who have not.

## 05

### Best Care No Matter Where You Live

Advocacy and empowerment program for patients facing a cancer diagnosis where health equity barriers may impact disease outcomes.

## PROGRAM SURVEY RESULTS:

### WHAT YOU WILL SHARE WITH YOUR HEALTHCARE TEAM?

> *"I have a voice to speak out what I believe would be the best treatment for my body and my health path. We will work together in making that decision."*

# digital sherpa™ Train-the-Trainer

## Focus on Digital Literacy

digital sherpa™ helps cancer patients (mainly 65 and older) and their families become more tech-savvy. By educating them in basic internet and social media skills, this empowers them to become more knowledgeable and proactive in managing their disease.

Train-the-Trainer equips community-based organizations and federally qualified health centers to deliver these digital literacy skills training workshops—online or in-person—to the cancer patients and caregivers in their communities.

> *"It was very informative and learned a lot about how to use computers."*
>
> Lazarex Cancer Foundation participant

To-date, digital sherpa™ has **empowered nearly 7,000 people** across the U.S.  In 2021, we were able to bring Train-the-Trainer to 9 cities across the country.

01 Adamsville, AL
02 Dallas, TX
03 Danville, CA
04 Davenport, IA
05 Louisville, KY
06 Orlando, FL
07 Philadelphia, PA
08 Phoenix, AZ
09 Redondo Beach, CA

# A Closer Look at CSC Arizona, a Train-the-Trainer Site

**first step**

»

When the staff at Cancer Support Community (CSC) Arizona heard about the digital sherpa™ Train-the-Trainer program, they knew it was just the kind of programming they were looking for. "We wanted to be able to help the more vulnerable members of our community," says Caitlin Morrissey, CSC Arizona's Executive Administrative Coordinator.

**challenge**

»

The goal was to help make things easier for the cancer patients they serve by helping them navigate things like social media, ride shares, and connecting them with loved ones as well as their healthcare providers. However, Director of Operations Kyle Jones recognized that some of their community members didn't have access to computers or devices.

**solution**

»

Kyle decided to use the 2021 digital sherpa™ Train-the-Trainer $2,500 start-up grant to purchase several Chromebooks so their members could actively participate in the digital sherpa™ program.

**outcome**

»

In response to participating in the program, Arcelia Lopez wrote, "Having the gift of the Chromebook changed my life mentally and emotionally and secured my future in having the confidence I needed to maintain my health. It changed me in a way that I didn't know was possible. It allows me to live in a way that I didn't know was possible."

# Best Care No Matter Where You Live

## Focus on Health Equity

### Outcomes as of 1/1/22

**06**

Disease Areas

**99,800+**

Total Reach

The Best Care No Matter Where You Live program provides tools for clear and effective communication between providers and BIPOC communities, encouraging self-advocacy, empowerment, and equal-access. It helps people with cancer feel more in control of their health journey and gain confidence around treatment decisions, no matter the geographic barriers.

This series includes:

- Powerful Self-Advocacy Vignettes
- Expert Videos Featuring Patients and Care Partners

## Survey Outcomes

**How will you approach your care team differently?**

*I won’t be afraid to fire my doctor if needed. This program has given the confidence boost I needed, and I will share with others.*

*I will first download the guide to know what questions to ask of my team, and make sure I bring a friend or family member with me to help me record and absorb the info presented to me.*

## Health Equity Initiatives

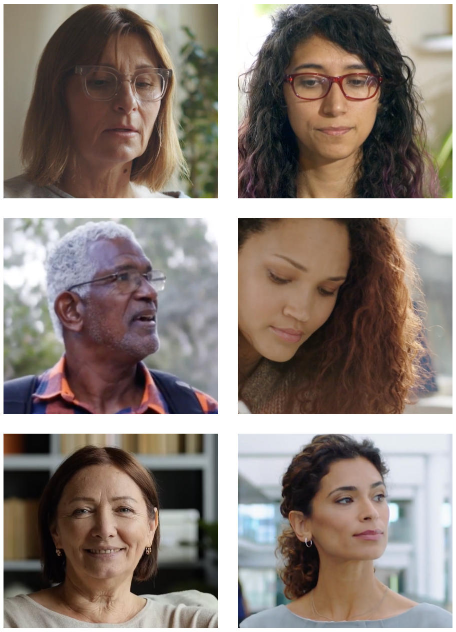
In addition to launching health equity programs with **Best Care No Matter Where You Live** and **Diverse Patient-to-Patient Clinical Trial Profiles**, PEN also introduced two new initiatives:

01 Inclusion Policy - Outlines PEN's commitment to inclusivity in all levels of our organization, governing staff, the Board, volunteers, business partners, and all external stakeholders, to deliver on our mission on behalf of cancer patients and their care partners.

02 Health Equity Committee - Promotes the highest levels of health equity and works to reduce current disparities in cancer communities.

| | |
|---|---|
| **89.8%** | Participants agree the program provided them with resources to avoid roadblocks to equitable care |
| **83.6%** | Participants feel the program made them feel more confident and empowered |
| **85.1%** | Participants would recommend this program |

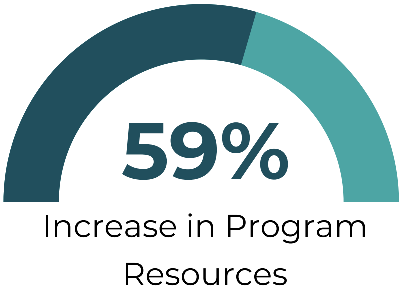
### Self-Advocacy Vignettes

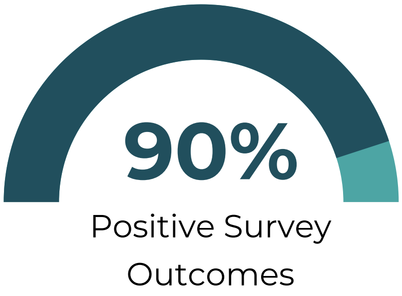


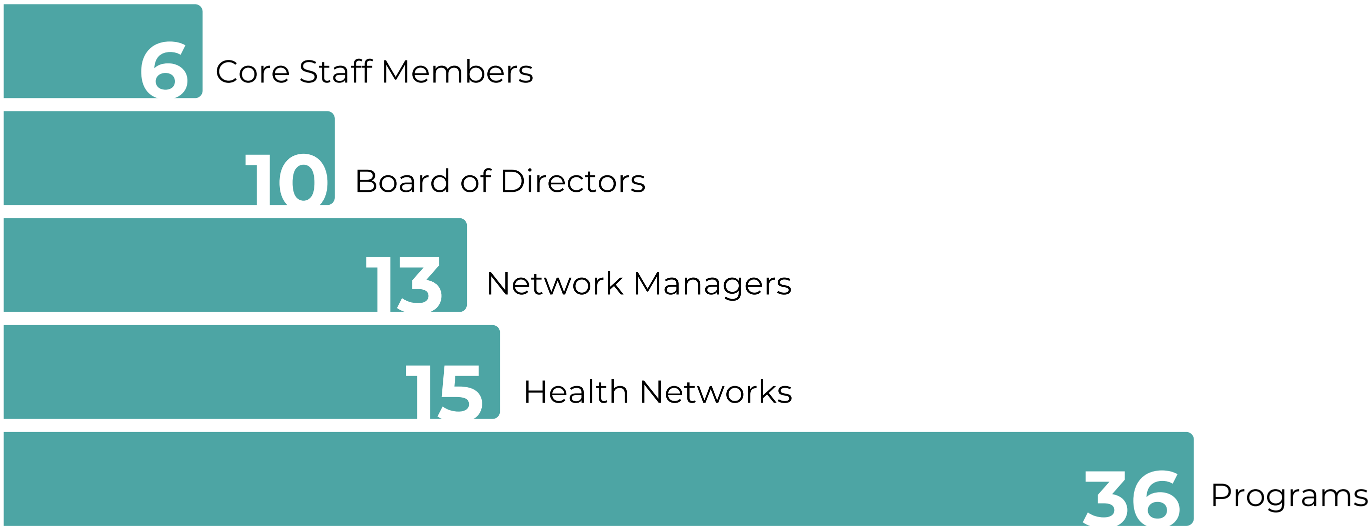
# capacity

In 2021, we doubled the number of programs we produced, thus, impacting more people with cancer than ever before. As of January 1, 2022, **our 2021 programs have touched over 345,700 lives**.

> ***The Patient Empowerment Network (PEN) is a great source of knowledge and support throughout the cancer journey for anyone who must take it. PEN's resources and programs are designed to empower patients to be their own best advocates. From better understanding their diagnosis all the way through to post-treatment options, PEN provides valuable knowledge and insights.***
>
> ***- Ray Parisi, PEN Board Member***







# partnerships

## 22

New Partner Organizations

## 64

Total Partners

### Partnership Activities Include:

- Webinar, event, or program promotion
- digital sherpa™ Train-the-Trainer implementation
- Participation in events, when applicable
- Sharing organizational or educational materials

# impact

Webinar participants feel more confident and empowered to speak up when they have questions about their care.

Webinar participants gained the knowledge and confidence to play an active role in care decisions.

## REPORTED LEARNINGS FROM PROGRAM SURVEYS:

> *I have a voice to speak out what I believe would be the best treatment for my body and my health path. We will work together in making that decision.*

> *The types of testing and treatment were explained so a patient could understand.*

> *Discuss with doctor and health team if I have received all available testing.*

> *How many options there are and that there are many factors that go into choosing one.*

> “As a cancer survivor, we all need to be reminded that we can be empowered and empower others.”
>
> -*@Megsie*
>
> Thank you, @Megsie, and everyone who purchased this year’s limited-edition shirt; your support amplifies patient empowerment!

# awards

### Voices of MPN 2021 MPN Hero: Jeff Bushnell

Recognized for his advocacy through the PEN Network Manager program, Jeff has been named a Voices of MPN 2021 MPN Hero.

The MPN Hero award is given to those who have demonstrated a strong commitment to making a difference in the lives of people with myeloproliferative neoplasms (MPNs). Jeff, whose wife Summer is living with myelofibrosis (MF), has accompanied and supported Summer on her MPN journey and has helped thousands of patients through the Network Manager Program.

### Web-based Digital Health Microsite Bronze Winner

Digitally Empowered™ was awarded a Digital Health Award, which honors the best digital health resources developed for consumers and health professionals.

# meet the team

# staff

**Andrea Conners**

Executive Director

One-Liner Award

Most likely to share wisdom through a clever catchphrase

**Kara Rayburn**

Digital Communications & Engagement Director

Craft Box Award

Most likely to have a beautifully colored spreadsheet

**Robin Barnes**

Development Director

Sticky Note Award

Most likely to take the best notes

**Nykema Mpama**

Network Manager Coordinator

Steve Irwin Award

Most likely to make a project an adventure

**Reagan LaBor**

Partnerships & Programs Coordinator

Yes Button Award

Mostly likely to say yes to challenging project

**Andrea Winchell**

Grants & Programs Administrator

Psychiatrist Award

Most likely to give the best advice

# board of directors

## New Board Members

### Sujata Dutta

Sujata leads a team of process engineers for Target Corp's fulfillment operations. She has proven experience in strategy planning and capacity expansion. She has a bachelor's in economics and a master's in international fashion marketing and engineering management. Sujata has worked in Asia, Europe, and North America in the hospitality, retail, and healthcare industries. She volunteers for the Asian Business Council at Target and supports underprivileged children in India as a volunteer for the Chance Foundation. After being diagnosed with Multiple Myeloma in December of 2019, she shifted her focus to patient advocacy. She provides support, inspiration, and empowerment to newly diagnosed patients and caregivers by sharing her story. She's out to 'normalize' cancer one 'bald' step at a time.

### Andrea Marquez

Andrea is a Mexican-American with 8+ years of experience in production, digital marketing, and communications. Currently, Andrea is a Podcast Host and Producer at Amazon, and works closely with the Amazon small business empowerment team. Andrea is also the creator and former host of LatinEQUIS, a bilingual podcast. Previously, Andrea managed accounts at Cien+ and the Hispanic Communications Network, where she drove societal impact by infusing cultural intelligence into long-term strategies for large brands. Andrea holds a B.A. in Political Science and Theatre Directing from Columbia University and an M.A. in Journalism and Legal Studies from Harvard University.

### Eric Vicks

Eric is a native of Cincinnati, Ohio and comes with over 15 years of policy and advocacy experience within the public health and primary health care arenas. He has used these platforms to address health disparities and to provide ordinary people in high need and under-resourced communities a voice in the policy-making process to shape issues important to them. His areas of expertise include, project planning and management, government affairs, grassroots development, and community relations particularly in communities of color. He holds a Bachelor of Arts Degree from the University of Cincinnati. He consults with and serves on several local boards in the D.C. area which work to improve health and promote equity.

# Board Members

**Darla Brown**
Board Chair

**Alyssa Gutjahr**
Board Secretary

**Ray Parisi**
Board Treasurer

**Jack Aiello**
Board Member

**LaWanda Byrd**
Board Member

**Nancy Gatshcet**
Board Member

**Sajjad Iqbal**
Board Member

**Scott Riccio**
Board Emeritus

# network managers

## New Network Managers

We are indebted to PEN Network Managers who pay it forward as the communities' human bridge to survivorship and an authentic representation of PEN's mission of helping patients and care partners find their voice, on their Path to Empowerment.

### Diahanna Vallentine Joined February 2021

Diahanna was a care partner to her husband who succumbed to multiple myeloma in 2013. Since then, she has made it her mission to help patients and caregivers empower themselves to speak up and to position themselves as partners in their treatment. Diahanna is a Board-Certified Patient Advocate and is currently the Financial Myeloma Coach for The Myeloma Crowd Foundation.

### Lisa Hatfield Joined July 2021

Lisa was diagnosed with multiple myeloma at the age of 49. Her work experience in the health care industry, along with her diagnosis, have led her to fiercely advocate for myeloma patients with regard to assembling a cancer care team, understanding diagnosis and treatments, and accessing adequate care for all.

## Network Managers

Jeff Bushnell

Sherea Cary

Cora Connor

Carly Flumer

**Gary Hooker** **Joined October 2021**

Gary is from the UK and was diagnosed with prostate cancer in January of 2011 with no symptoms and a prognosis of up to 2 years to live. He participated in a clinical trial which he believes gave him his life back and now continues to advocate for others.

**Christine Wu** **Joined October 2021**

Christine was diagnosed with Stage 4 ROS1+ lung cancer metastatic to the brain in 2015. She believes having cancer is like a second chance to live again and has devoted herself to the cause of changing lung cancer into a chronic disease.

**Sasha Tanori** **Joined October 2021**

Sasha was diagnosed with AML in December of 2017 in her early 20s. She believes patient advocacy is extremely important because just knowing you aren't alone on your health journey makes such a difference and being able to talk to someone else who knows exactly what you're going through is such a relieving feeling.

**Summer Golden** **Sajjad Iqbal** **Mary Leer** **Volleen White**

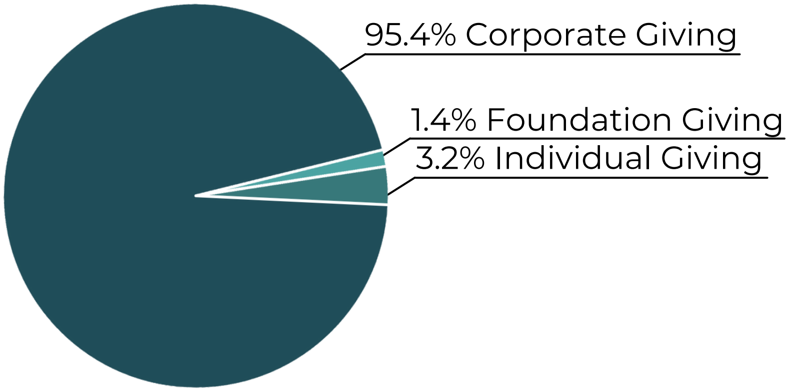
# fundraising

At Patient Empowerment Network, we're a digital organization by choice. By operating virtually, we can serve far more people by meeting them where they are, while minimizing overhead costs.

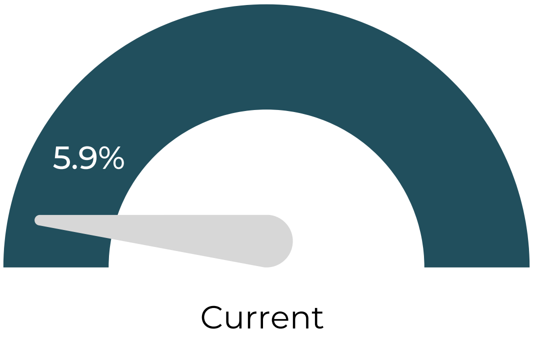
Through our efficient use of donations, we contribute more than 87% of revenue into programs. And as our reach and impact continue to grow, so do donor investments. In 2021, individual giving increased 46% and corporate giving increased 60% from 2020.

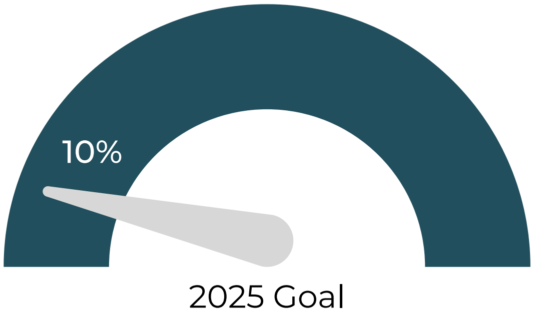
However, to ensure our adaptability to the cancer community's changing needs, especially around health equity, digital literacy, and clinical trials, we are seeking to increase unrestricted giving to at least 10% of our annual operating budget by 2025.

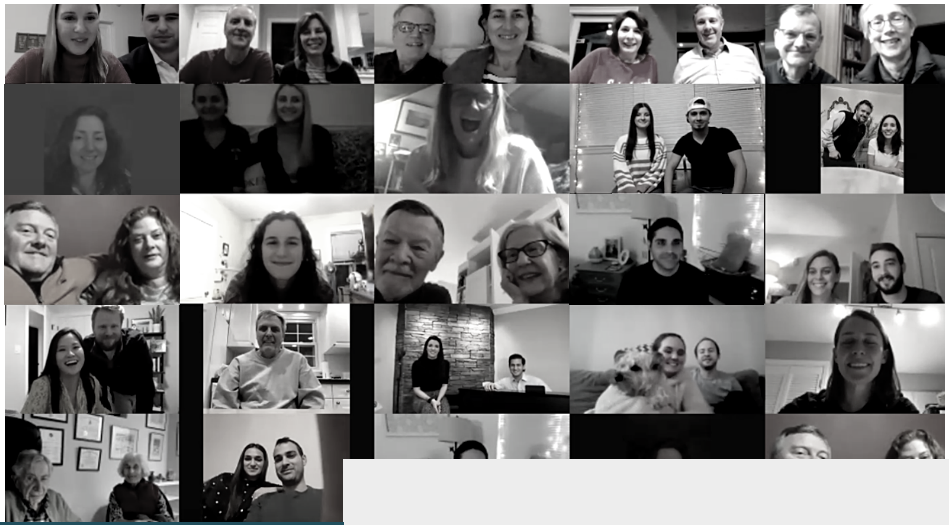
## Revenue Sources



## Unrestricted Revenue

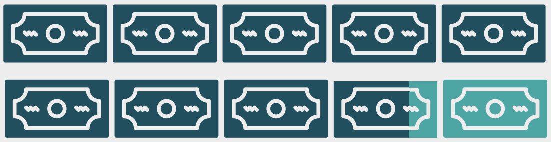






> We are grateful to the individual donors, foundations, and corporate sponsors who help us to bring education and empowerment to cancer patients and care partners. Because of you, far more people with cancer are achieving the best possible outcomes.

## Revenue Application



87% of revenue goes directly back into our programs, and 13% goes to management.

# from the executive director

## Onward and upward!

Dear friends,

When I reflect on the past few years since we launched Patient Empowerment Network's first strategic plan, I'm reminded of the words of Martin Luther King Jr., "You don't have to see the whole staircase, just take the first step."

Launching an ambitious strategic plan in 2019 was the first step toward better serving you and others in our network who have been impacted by cancer. Since then, we have learned and accomplished a lot. Specifically, we spent time listening and learning about what you need to successfully navigate the path to empowerment leading to better health outcomes.

Thanks to our friends from Diverse Health Hub who conducted a Snapshot Survey of PEN's network, we learned that many of you have either been recently diagnosed with cancer or have recently started caring for someone with cancer. This means that, for many of you, the resources and information you gain from PEN's programs help guide your early treatment decisions. We take this responsibility seriously and will continue to focus on meeting your needs and empowering you to actively share in treatment decision-making with your care teams.

While we've had many successes over the past few years, we've also had our share of disappointments.

> We spent time listening and learning about what you need to successfully navigate the path to empowerment leading to better health outcomes.

One challenge we have faced is securing funding to produce programming in cancer types that disproportionally impact underserved communities. Renal Medullary Carcinoma (RMC), a rare but often lethal kidney cancer that predominantly occurs in young Black people with the sickle cell trait, often goes undiagnosed until late stages present significant, life-threatening symptoms. In partnership with our RMC Network Manager, Cora Connor, a tireless advocate for RMC, and other partners, we've worked hard to educate people about RMC, but we need funding to do more.

2022 marks the final year of our current strategic plan and we will spend significant time this year working on what comes next. Please reach out to me directly if you would like to be a part of mapping our future.

Thank you for being a friend of PEN. I continue to be incredibly grateful for our network of patients, care partners, healthcare providers, donors, partners, and volunteers. With your continued support, we will continue to move forward and, one day, see the whole staircase.

Wishing you a year full of good health and happiness.

Andrea Conners

Patient
Empowerment
Network

## Stay Connected

powerfulpatients.org/connect