

## **Patient Empowerment Network**

## 2020 Annual Report



## Welcome to Patient Empowerment Network's

### 2020 Annual Report



I tuned in today to your Zoom presentation and found it the best I have ever attended and by far the most patient-friendly in terms of patient understanding.



Look for the quotations throughout this report for more feedback from our network.

+69%

Increase In PEN's community

+543%

Increase In PEN's video views



### **Table of Contents**

Introduction Message From Our Board Chair	3
COVID Response	5
The Path to Empowerment	7
Introduction of Network Managers	9
2020 Programs	11
Fundraising	15
Capacity	16
On Board With PEN	17
Looking Ahead to 2021	18
The Value of PEN	19
Meet the Team	21

### **Introduction Message From**

### **Our Board Chair**



"We have reached more cancer patients and care partners than ever, reaching 133% more patients than the previous year."

**Darla Brown**Board Chair

Dear Friends,

As I reflect back on 2020, a year of incomprehensible loss for so many, I ask you to join me in a virtual moment of silence to remember those loved ones we have lost and to honor and acknowledge the sacrifices of our healthcare and essential workers as they continue to provide care to people with cancer through the global COVID-19 pandemic.

Despite the overwhelming challenges that 2020 brought to bear, under the leadership of PEN's Executive Director Andrea Conners, the Patient Empowerment Network made significant progress forward in our mission to provide resources to cancer patients and care partners so that they can receive the best care possible and achieve the best possible outcomes.

We are one year into our three-year Strategic Plan that we established in 2019. At that time, we outlined four areas of focus: 1) Empower the patient journey, 2) Expand PEN's reach and increase visibility, 3) Expand our partnerships, and 4) Build new funding sources. Despite the challenges of 2020, we have reached more cancer patients and care partners than ever, reaching 133% more patients than the previous year.

We expanded our Path to Empowerment content into additional cancer areas, including metastatic breast, thyroid, head & neck, and prostate. In response to the pandemic, our popular digital sherpa™ Program went 100% virtual, which allowed us to continue to provide online training to empower cancer patients.

I extend the board's gratitude to the PEN team for their tireless efforts towards PEN's mission: Andrea Conners, Executive Director, Kara Rayburn, Director of Digital Communications and Engagement, and Robin Barnes, Director of Development. Robin joined PEN in 2020 and has expanded our fundraising reach in innovative and impactful ways. In addition, I want to recognize Tamara Lobban-Jones for her innovative work to build and launch the award-winning Network Manager Program and to Nykema Mpama for her outstanding work to move the program forward.

Thank you also to my fellow board members who continue to volunteer their time and resources towards PEN's mission: Nancy Gatchet, Sajjad Iqbal, Jack Aiello, Lawanda Byrd, Scott Riccio, and our General Counsel, Tom Pedreira. Our board grew this year as we welcomed Ray Parisi, Asalia Goldberg, and Alyssa Gutjahr. In addition, we send a special thank you to Joan Justice who retired from the board in 2020. Joan served as PEN's Executive Director from 2014 to 2017 and then as a Board Member for three years. Joan inspired me and so many others in her advocacy work while at PEN. Thank you, Joan!

As we look to 2021, we are committed to expanding our core mission to include telling the stories of Black, Indigenous, and People of Color (BIPOC) who are living with cancer. The pandemic has highlighted the longstanding health inequities in the U.S. healthcare system. In response, the PEN board recently established a Health Equity Committee tasked with expanding our existing programs and creating new programs for BIPOC communities.

On behalf of the board, I thank the entire Patient Empowerment Network community: our Network Manager volunteers, our program volunteers, our donors, our partners, and you. I look forward to our continued work together to support cancer patients on their journey to empowerment.

Sincerely,

Darla Brown

Inda Brown

### **COVID Response**

### **PEN-Powered Activity Guides**

Having cancer or caring for someone with cancer can be lonely and extremely isolating. Adding a global pandemic on top of dealing with cancer is overwhelming to say the least. In March 2020, Team PEN came together to assess the needs of our network and to determine what support we were uniquely positioned to provide during this unprecedented time.

We determined that prioritizing mental health, connecting people, and continuing to regularly engage with our network was where we needed to concentrate our efforts. On March 20th, we launched the first PEN-Powered Activity Guide focusing on Sharing Inspiration, Ideas, and Encouragement. We went on to launch four additional volumes culminating in our last guide being published on October 27th focusing on Tools for Harnessing Your Empowerment Skills.









### digital sherpa™

The digital sherpa™ program is typically delivered as an in-person workshop. This year, to keep our students and participants safe, we delivered the program virtually via Zoom. While the transition to virtual was challenging, the program continued to be a great success. Fueled by the kindness of student volunteers from across the U.S., older cancer patients can now access potentially life-saving online healthcare resources.



### **Spotlight on Digital Literacy**

Only 12 percent of adults have a proficient level of health literacy. One of the biggest hurdles to learning about health and healthcare decisions is the ability to access and use technology.

We developed the Digitally Empowered<sup>™</sup> program to help cancer patients become more techsavvy. Through a series of easy-to-follow video modules, coupled with resource guides, we are educating patients on technology and online support tools. Course objectives include:



Find the information and support you need to empower you and your loved ones during your cancer journey.





"PEN's Digitally Empowered™ course helped me to find out about additional organizations to assist me as a caregiver, and for my mom, as a patient. Now we can view health records, schedule appointments, and access wellness activities, all online."

### The Path to Empowerment

What differentiates PEN from other cancer advocacy groups is that we take health literacy a step further; our free online resources educate, then **ACTIVATE** cancer patients and their care partners to become co-decision makers with their healthcare teams. By insisting on the most current and personalized care available, empowered patients achieve better treatment outcomes —supporting this is at the heart of everything we do.

We created the Path to Empowerment, a framework designed to help patients and care partners find their voice at every step of their cancer journey. Since 2019, all of PEN's programs align with at least one step along the Path to Empowerment.



### **Newly Diagnosed**

The Pro-Active Patient Toolkit



## Access & Affordability

- Diverse Partners in Your Myeloma Care
- CLL TelemEDucation
- digital sherpa™
- Digitally Empowered™





### **Testing**

• INSIST! on Better Care



## Treatment & Clinical Trials

• The Pro-Active Patient Toolkit 2.0



## Whole Patient Support

• The Empowered #patientchat



## What's Next?

• The Network Manager Program



### **Introduction of Network Managers**



Sherea Cary
Care Partner
Network Manager

Sherea found her calling in caregiving nearly two decades ago. She provided leadership then to her family as they helped her father survive a prostate cancer diagnosis in 2000.



Cora Connor RMC Network Manager

Cora founded R.M.C. (renal medullary carcinoma) Inc. to educate the public and healthcare professionals while enhancing the lives of individuals fighting a rare kidney cancer, RMC.



Carly Flumer
Thyroid Cancer
Network Manager

While being diagnosed with the "C" word at such a young age was a surprise, as it would be to anyone, Carly found strength, support, & inspiration in sharing her cancer journey on social media.



Summer Golden & Jeff Bushnell

**MPN Network Managers** 

Summer Golden and Jeff
Bushnell have been married for
over 20 years. When Summer
was diagnosed with
myelofibrosis (MF), Jeff took on
the role of care partner and
advocate.



Sajjad Iqbal Head & Neck Cancer Network Manager

Sajjad is a physician, pediatrician and cancer survivor. Almost 17 years ago, Sajjad diagnosed himself with parotid cancer.



Mary Leer Breast Cancer Network Manager

Mary was diagnosed at 67 with stages IA & IIA ductal invasive breast cancer. She understands the critical need to repair inequitable access to healthcare for better health outcomes and shares her story to help others.



Honora Miller Multiple Myeloma Network Manager

Honora was diagnosed with myeloma at age 49 in 2015. She is passionate about patient empowerment and sharing information & experiences with patients and caregivers to help us all achieve the best quality of life possible.



Heather Smith Lung Cancer Network Manager

Heather was diagnosed with stage IV ALK+ lung cancer at 34. Through a blog, a virtual support group, fundraising, & telling her story to the local news, she's become an advocate for lung cancer patients.



Volleen White
CLL
Network Manager

Volleen is a chronic lymphocytic leukemia, B-cell type, stage IV patient. She is a survivor and a fighter who looks forward to advocating for others.

Our Network Manager program continues to grow!
We are now ten highly passionate empowerment ambassadors strong from all over the country, engaging PEN's network of cancer patients and families and serving as a direct conduit of empowerment across several therapeutic areas.

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.

### **Awards and Recognition in 2020**

### **Patient Advocates Turned Award-Winning Network Managers**



2020 MPN Hero

Summer Golden, recognized for her advocacy through the PEN Network Manager program, has been named a Voice of MPN 2020 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).



Reuters Patient Champion Award Finalist

Dr. Gerri Smoluk was a PEN Acute Myeloid Leukemia (AML) Network Manager and was named a finalist for the Reuters Patient Champion Award in the Patient Advocate category. A drug development scientist and patient advocate, until her untimely passing in July 2020, Gerri made it her mission to help patients ask the right questions of their care teams.

### **2020 Programs**



Yesterday's program was absolutely outstanding!! I am meeting with my oncologist today to discuss treatment, and this program could not have been more timely or pertinent.

Thank you! Thank you!



### **Highlights**



**18** Programs



32 Live Events



**37** Experts & Patients



2018 Live Attendees



## Take a look at a few of your favorites...



## **INSIST! On Better Care**

Educates and empowers patients and care partners to speak up and insist on better care.



# Diverse Partners in Your Care

The goal of this program is to provide actionable and educational resources for myeloma patients and care partners.

### **INSIST!**

### On Better Care

INSIST! is designed to empower and give cancer patients and care partners swift and actionable information to speak up and insist on better care and personalized treatment options.



### +18,500 Reach

INSIST! has impacted and touched over 18,500 patients and care partners across these five cancer types:

- Acute Myeloid Leukemia (AML)
- Chronic Lymphocytic Leukemia (CLL)
- Lung Cancer
- Metastatic Breast Cancer
- Prostate Cancer

### **Key Learnings**

The difference between targeted therapies and other treatments, i.e., immunotherapy.

Good information on what mutations are and how they are determined.

#### **Outcomes**



5 Webinars



13 Experts



542 Live Attendees



63 Videos



8 Resource Guides

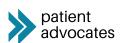
### **Diverse Partners in**

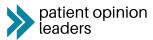
### **Your Care**

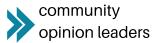
Provides tools for clear and effective communication between providers and patients, encourages **self-advocacy** and **empowerment**, and **promotes equal access**. The program includes information on achieving health equity and bridging gaps between diagnosis and treatment from:











### **Main Takeaways**



+19,500 Reach



7 Videos



5 Experts and Patients



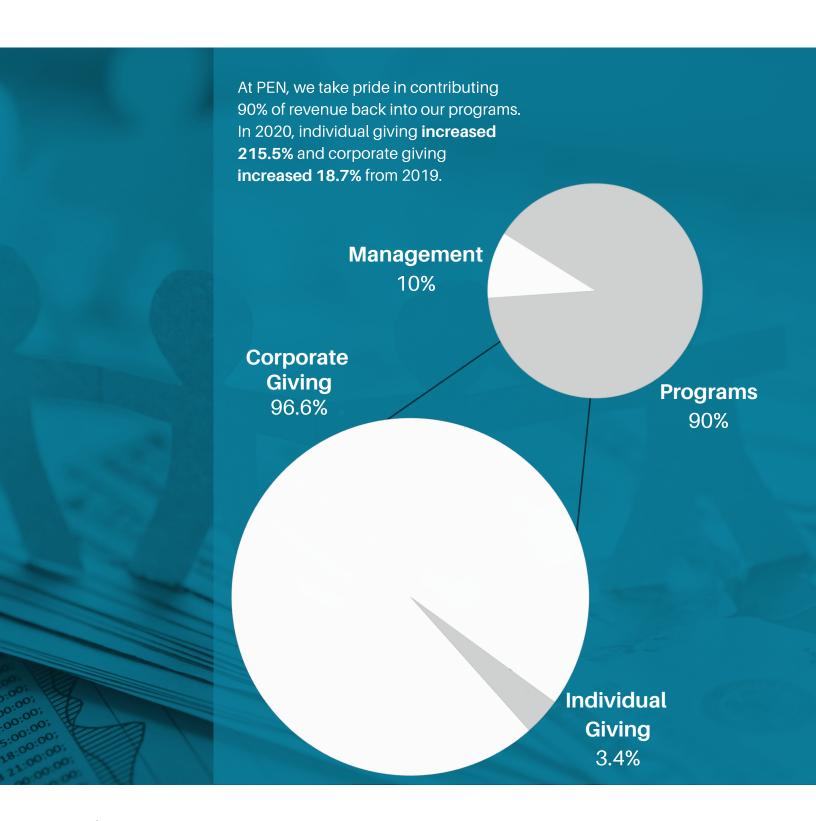
2 Resource Guides

1 will be more persistent in making sure that my questions are answered to my satisfaction. This is not always easy to do.



of participants said they are more likely to share their story with others to raise awareness for equitable care.

### **Fundraising**



### **Capacity**



"Patient Empowerment Network (PEN) has helped me achieve a better outcome by publishing information specific to my diagnosis. I now have a methodical approach to dealing with myeloma, including how to access treatment and important information regarding treatment decisions."



Network Managers



Advocacy Partners



9

**Board of Directors** 



Board of Digital Advisors



**Volunteers** 



5

**Core Staff** 

### **Meet the Board**

Patient Empowerment Network is excited to announce the addition of three new members to our diverse and talented board of directors.



#### **ASALIA GOLDBERG**

Asalia is a passionate patient advocate who works in healthcare management with Boston Consulting Group (BCG) and has quite a bit of experience working with Fortune 500 companies in the biopharmaceutical industry where she has helped launch innovative therapies for oncology, rare disease, and heart disease. She has served as associate director of the

Lymphoma Research Foundation and has been involved with Red Cross and Save the Children. She believes passionately in health equity and eliminating the disparities in healthcare through advocacy for patient education and empowerment.



#### **ALYSSA GUTJAHR**

Alyssa is a cyber security expert and brings a great deal of digital knowledge to the board. She has worked as a software development consultant for IBM and as a product manager for CNBC Digital. Currently, she is a program director at NBCUniversal where she manages cyber security programs for the company. She is also active in a community outreach

program that connects professional women in her company with young women in the community, hoping to inspire interest in science, technology, engineering, and math (STEM) careers.



### **RAY PARISI**

Ray brings a wide array of skills and experience to the board. During his career he has been a financial analyst, a journalist, and a communications manager. He led corporate marketing and communications teams for big-name corporations Freddie Mac and AstraZeneca, helping to navigate the companies through challenging situations that included federal investigations for

Freddie Mac, and corporate restructuring for AstraZeneca. Currently, he is president of RJP communications LLC, where he specializes in public affairs and client communications.



DARLA BROWN

Board Chair



SAJJAD IQBAL
Board Secretary



JACK AIELLO

Board Treasurer



**LAWANDA BYRD**Board Member



NANCY GATSCHET

Board Member



SCOTT RICCIO

Board Member

## Giving Thanks, Inspiring Innovation, and Looking Ahead

2020 proved a challenging year for everyone whether we lost a loved one, a job, or simply a sense of peace and security. Amidst the challenges, and beyond what anyone could have anticipated, 2020 demanded innovation from us all. Innovation and technology brought us together for Zoom celebrations with family and friends, it brought us new ways of working and collaborating with colleagues, and most importantly it brought us a life-saving vaccine.

For PEN, 2020 delivered new challenges that were met head-on with innovative solutions. As you saw throughout the pages of this Annual Report, Team PEN rose to meet these challenges and worked hard to support our network in new and innovative ways. We continued to deliver our high value programs virtually ensuring that we were always available -- 24 hours a day, 7 days a week, all 365 days of 2020 -- to all who needed us.

In 2021 the innovation must and will continue. Guided by our strategic plan, we will continue to launch new programs along the Path to Empowerment Framework, expand our tools and resources into new cancer types, grow our network of patients and care partners, work with new and existing partners, and continue to find innovative ways to help each of you find your voice and be your own best advocate during your cancer journey.

We will continue to focus on digital literacy, bridging the digital divide and equipping patients and care partners with the knowledge and technology skills they need to make informed healthcare decisions that create better outcomes for everyone.

We will explore the systemic issues that exist within our healthcare system leading to health inequity and we will, in collaboration with our friends and partners, chart a bold new path forward.

With the help of PEN's newest staff member, Reagan LaBor, we will focus on building and fostering innovative partnerships and collaborations to advance our mission

Thank you for being a friend of PEN. I am constantly humbled by and extremely grateful for our network of patients, care partners, healthcare providers, donors, partners, and friends. With your support and a little innovation, anything is possible.

Andrea Conners

Wishing you a year ahead full of good health and happiness,

Andrea Conners
Executive Director

### The Value of PEN

The best cancer care happens when you're empowered to ask the right questions, at the right time. But where to start? Start here, with this video series, to learn how we're helping to create better outcomes for empowered patients.

Your Path to Empowerment **Learn More About Your Diagnosis** 

Free Resources for Cancer Patients

Community and Connection

**Bridging the Digital Divide** 

### **Stay Connected**



Sign up to receive our newsletters to be the first to hear about our newest blogs and videos.





Join our Facebook group for a safe space to have meaningful dialogue with other patients and care partners like you.

**START HERE** 



Receive personalized support from our Network Managers by texting +1 833-213-6657

**START HERE** 

### **Meet the Team**



ANDREA CONNERS

**Executive Director** 



KARA RAYBURN

Digital Communications & Engagement Director



ROBIN BARNES

**Director of Development** 



NYKEMA MPAMA

Network Manager Coordinator



REAGAN LABOR

Partnerships and Programs Coordinator