ANNUAL REPORT 2018

> **I was diagnosed in July of 2014 with lymphoma** and have been in treatment pretty much since then. Two weeks ago, I had my last chemotherapy appointment so we're crossing our fingers that I'll have a little time before it comes back.
>
> I have a chronic type of lymphoma and I've been through five different types of treatment. Which is why I've **had the opportunity to use the Cancer Support Community's Open to Options®** more than once.
>
> **It definitely helped me expose all my fears,** but it really helped **pinpoint what my priorities were.** We have all these ideas about how cancer is and how treatment is going to be. Open to Options helped me clarify what I wanted.

CANCER SUPPORT COMMUNITY

GILDA'S CLUB WORLDWIDE

It gave me a script to carry with me to my doctors' visits, so I wouldn't forget what was important to me, both in the present and going forward. Those initial visits can be so fraught with emotion and fear, so working one-on-one with a licensed professional at CSC San Francisco Bay Area **to figure out what I wanted before I got to the doctor's office, was really key.**

EVERY PATIENT HAS A STORY TO TELL.

FOR THEM, OUR COMMUNITY IS STRONGER THAN CANCER.

What surprised me was **how helpful it still was two years later,** when I faced yet another treatment crossroads. I was a seasoned patient at that point, but **Open to Options helped me pinpoint my new priorities,** which had evolved a great deal from the time of my original diagnosis. Working through the program **helped me find the truth of what I wanted, needed, and expected. Thank you, CSC!**

—Liz Fajardo, Member,
CSC San Francisco Bay Area

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FROM OUR CEO

First off, I want to thank you.

Whether you are a patient or caregiver who shared your story, a corporate ally, or an individual donor—this report belongs to you.

As a result of your generosity and decision to share your story, we are able to provide relevant and highly personalized support and navigation—when and where it is needed most.

The Cancer Support Community is the most trusted and relentless ally for anyone who is managing the realities of this disruptive disease and trying to get back to normal. **More and more individuals are turning to us because we "speak cancer."** We are providing face-to-face support at more locations, expanding our digital resources, conducting cutting-edge research, and advocating for patient-focused policies at all levels of government.

As you read these individual stories and see the statistics, just know that our belief is that Community is Stronger than Cancer. That means we want you to share this information to ensure anyone touched by this diseases knows he or she is not alone—and has an ally like the Cancer Support Community made possible with your unyielding support.

Kim Thiboldeaux
CEO

FROM
OUR BOARD CHAIR

IT IS SUCH A PRIVILEGE TO SERVE AS THE CHAIR OF THE CANCER SUPPORT COMMUNITY'S BOARD OF DIRECTORS.

Our annual report tells the story that **we listen to patients and caregivers to ensure that our resources align with their needs.**

On a personal note, the 2018 report is especially meaningful because of two milestones. As part of the close-knit group of people who founded The Wellness Community in Philadelphia, which is now CSC Greater Philadelphia, it was amazing to celebrate that affiliate's 25th anniversary. We marked another milestone in Philadelphia, celebrating the 10th anniversary of the Research and Training Institute, based in that city. The Institute went from an idea to a vibrant program presenting unique patient-focused studies at 12 major health-care conferences.

These anniversaries come as we have witnessed many significant advances in treating cancer. But, as this report illustrates, nothing takes the place of the power, inspiration, companionship, and connection that our in-person support, digital resources, and educational materials provide patients and their loved ones.

As we reflect on where we were 25 or 10 years ago, our pledge for the future is built on a simple principle: Community is Stronger than Cancer.

Jill H. Durovsik

Jill Durovsik
CHAIR

NEWLY DIAGNOSED

EMOTIONAL STATE

In shock, overwhelmed,
not in control

GOALS

Get clear and concise guidance in writing

Organize finances

Keep kids feeling secure

TYPICAL QUESTIONS

What are my options? Do I need surgery? Chemo? Will I lose my hair?

Who's taking care of me? Who's on my team and what do these people do?

Can anyone help me navigate these insurance forms?

How will this affect my job?

Am I going to be OK?

IN TREATMENT

EMOTIONAL STATE

Still scared but better informed

Trying to manage the "new normal"

GOALS

Stay as healthy and strong as possible during treatment

Keep family and friends informed

Find support to help with household tasks, childcare, travel to/from treatment

TYPICAL QUESTIONS

How can I minimize the side effects of meds?

Who can I talk to who's been through this?

Are there support groups?

Who can help me navigate insurance and financial challenges?

POS
TREATM

EMOTIONAL

Scared, lonely,
fear of the future

GOALS

Stay healthy

Help others going th
same journey

TYPICAL QUE

Will it come back?

What can I do to pro
going forward?

Who is out there tha
for people like me?

THE PATIEN

T
MENT

REMISSION

RECURRENCE

STATE

rough

ESTIONS

tect my health

t can advocate

EMOTIONAL STATE

Relieved, grateful, motivated maintain healthy lifestyle

GOALS

Return to "before" life for self and family

Pay it forward and help others go through the same journey

TYPICAL QUESTIONS

What are the chances of recurrence, metastasis?

What are the long-term effects of treatment, meds?

How to manage post-treament finances and career

EMOTIONAL STATE

Scared

Depressed

GOALS

Focus on recovery and what's important now

Keep family and friends informed

Do what you can and ask for help with what you cannot

TYPICAL QUESTIONS

Are there new treatment options or clinical trials?

Who can help me prepare advance directives and medical power of attorney?

What else can I do to support my family through my illness?

Will I be OK?

IT JOURNEY

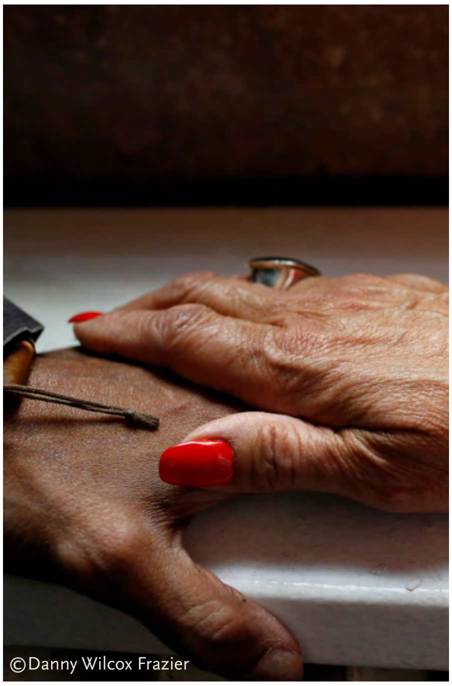

CANCER SUPPORT COMMUNITY
A Global Network of Education and Hope

THE AFFILIATE NETWORK: **AT THE HEART OF THE COMMUNITY**

WHEN A PERSON IS FIRST DIAGNOSED WITH CANCER, LEARNING TO NAVIGATE THE “NEW NORMAL” CAN BE OVERWHELMING. OUR WORLDWIDE NETWORK OF AFFILIATES AND HEALTH CARE PARTNERS IS OFTEN THE FIRST STOP ON THEIR JOURNEY AND PROVIDES A SAFE HARBOR WHERE THEY AND THEIR FAMILIES FIND CRITICAL INFORMATION, TOOLS, AND SERVICES FOR MANAGING THEIR DISEASE WHILE LIVING THEIR LIVES.

INSTITUTE FOR EXCELLENCE IN PSYCHOSOCIAL CARE

Supporting the whole patient—attending to the entirety of an individual's emotional, physical, and lifestyle needs—is at the heart of what we do. In 2018, we established the Institute for Excellence in Psychosocial Care with the goal of facilitating greater adoption of and access to best practices in psychosocial care throughout the cancer community.


©Danny Wilcox Frazier

REACHING OUT AND TOUCHING THOUSANDS

477,500

Visits to Affiliates and Health Care Partners

77,912

Total People Served at our Affiliate and Health Care Partner Locations

23,000

Calls to our free helpline

78,808

Total Number of Programs Offered by Affiliates and Health Care Partners

CANCER AT THE CROSSROADS

ANNUAL LEADERSHIP CONFERENCE

Indianapolis was the setting for last summer's Affiliate Leadership Conference, one of the best attended in our history. More than 115 attendees came together for this four-day event, which included a CEU-eligible pre-conference. Popular sessions included a presentation by Chase Jones about the Biden Cancer Initiative and a CEU-eligible session with Laura Grimes, LCSW, on integrating cancer care for LGBTQI+ populations. Another highlight? A minor league baseball game at Indianapolis's Victory Field.

BIDEN CANCER INITIATIVE

COMMUNITY SUMMITS

CSC has been involved with the Biden Cancer Initiative since it was first launched in 2017. This past September, in conjunction with the Biden Cancer Summit in Washington, DC, we organized more than 38 Biden Cancer Community Summits, inspiring communities to have meaningful conversations and develop shared action plans to improve the cancer journey.

Affiliate leaders attending the annual conference in Indianapolis

One of the many presentations held during the Biden Cancer Summit.

COMMUNITY HUB

In August 2018, CSC was awarded a Wisetail Works Grant to underwrite the Community Hub, an affiliate and health care partner intranet that offers continuing education opportunities, discussion boards, and enhanced communication services. Expected to launch in 2019, the Community Hub is designed to strengthen our internal community and, more importantly, support the mission of the Institute for Excellence in Psychosocial Care by serving more people impacted by cancer.

Patients and affiliates staff work together on refining recipes for our new Eating Well series.

EDUCATION: EMPOWERMENT & SUPPORT

WHAT CAN I EAT WHEN I CAN BARELY LOOK AT FOOD? HOW WILL I PAY FOR MY TREATMENT? WHAT DO I TELL MY CHILDREN? HOW DO I COPE? IS A CLINICAL TRIAL RIGHT FOR ME? FOR PATIENTS WITH CANCER, THERE ARE ALWAYS MORE QUESTIONS THAN ANSWERS. WE RESPOND TO THEIR CONCERNS WITH ACTIONABLE AND RELEVANT INFORMATION VIA AWARD-WINNING EDUCATIONAL MATERIALS (PRINT, PODCASTS, VIDEOS, SOCIAL MEDIA) AND OFFER REAL-TIME SUPPORT VIA OUR PROFESSIONALLY STAFFED TOLL-FREE HELPLINE AND OPEN TO OPTIONS® PROGRAM.

This year, we published new and updated resources on nearly 20 different cancer-related topics, including:

EATING WELL

We expanded our Frankly Speaking About Cancer series with three new publications focused on diet and nutrition: *Eating Well During Cancer Treatment*, *Eating Well For Cancer Survivors*, and *Eating Well With Head & Neck Cancer*.

The booklets, which feature real patients and CSC affiliate members, are rich with tips on how to overcome the special nutritional challenges individuals face before, during, and after treatment. Special recipes to support healing, increase appetite, or help with specific eating problems are included and also featured on our website and Pinterest boards.

FRANKLY SPEAKING ABOUT CANCER

Eating Well During Cancer Treatment

A healthy diet is an important part of a cancer patient's journey before, during, and after treatment. Eating healthy can help prevent weight loss, lack of appetite, and other side effects of cancer treatment. It can help you feel better and respond better to your cancer treatment.

This booklet addresses how cancer patients can cope with common eating problems faced during treatment, like nausea or mouth sores. It also features recipes to help with common problems.

If you are not having any eating problems, see our *Nutrition for Cancer Survivors* booklet, at www.CancerSupportCommunity.org/SurvivorNutrition. If you are a head and neck cancer patient, see our *Eating Well with Head and Neck Cancer* booklet, at www.CancerSupportCommunity.org/HNCEating.

CANCER SUPPORT COMMUNITY

Nausea

Almond Banana Wheatberry Cereal

Dry Mouth

Cranberry Coconut Popsicle

Quinoa Tabbouleh

LUNCH RECIPE

Prep time: 15 minutes | **Cook time:** 15 minutes | **Serves:** 6

Perfect for a lunch, light dinner, or side dish, this quinoa tabbouleh is nutritionally balanced and full of bright flavors. Unlike traditional tabbouleh, this version is high in protein and fiber with the use of whole grain quinoa. For a complete meal, add seasoned ground chicken or turkey breast for a fresh and hearty salad.

INGREDIENTS

1 cup quinoa, uncooked
1 cup diced tomatoes
1 cup diced cucumbers
½ cup diced red bell peppers
1 cup fresh parsley, chopped
½ cup fresh mint
2 lemons, juiced
2 Tbsp olive oil
½ cup feta cheese (optional)

DIRECTIONS

1. Rinse and cook quinoa according to package instructions.
2. While quinoa is on the stove, combine the tomatoes, cucumbers, peppers, and herbs in a large bowl.
3. Once quinoa is cooked and cooled, add into the vegetable and herb bowl.
4. Add lemon juice and olive oil.
5. Top with feta cheese if desired.

DID YOU KNOW? Tomatoes are a healthy source of lycopene, an antioxidant which may reduce heart disease risk.

NUTRITIONAL DATA: Per serving: 200 calories, 9 grams fat, 2.5 grams saturated fat, 10 mg cholesterol, 125 mg sodium, 23 grams carbohydrate, 3 grams dietary fiber, 7 grams protein

Swallowing

Banana Melon Smoothie

Change In Taste

Creamy Beet Hummus

Chocolate Mint Smoothie

SMOOTHIE RECIPE

Prep time: 5 minutes | **Serves:** 2

This smoothie tastes like an indulgent dessert in a glass but is packed with nutrition. The avocado adds healthy monounsaturated fats, which are healthy for cancer survivors. The oats provide fiber and bulk to keep you full and promote healthy bowel movements. The almond milk and peanut butter provide protein to promote healing after cancer treatments. Try this smoothie as a healthy dessert or afternoon snack and you won't be disappointed.

INGREDIENTS

2 cups chocolate almond milk
1 Tbsp peanut butter
1 Tbsp cocoa powder
5-8 mint leaves (depending on size and how minty you want the smoothie)
1 cup oats, uncooked
1 avocado
1 cup ice

DIRECTIONS

1. Place all ingredients in high-powdered blender.
2. Blend until smooth.

NUTRITIONAL DATA: Per serving: 390 calories, 21 grams fat, 3 grams saturated fat, 0 mg cholesterol, 220 mg sodium, 40 grams carbohydrate, 6 grams dietary fiber, 11 grams protein

TIP: If you have leftover smoothie, pour into popsicle mold for a refreshing and delicious treat!

> The Cancer Support Community is an invaluable organization for all individuals along their cancer journey. It meets you where you are and provides resources developed by professionals yet approachable during a stressful time. **During a time where I felt very helpless, I was able to cook the cheesy chicken millet bake for my dad and felt that, in a small way, I was contributing to his healing.**

—Jessica Merrill, Sudbury, MA (pictured on the far left with her sisters) whose family uses *Frankly Speaking About Cancer: Eating Well with Head & Neck Cancer*

KNOWLEDGE IS POWER

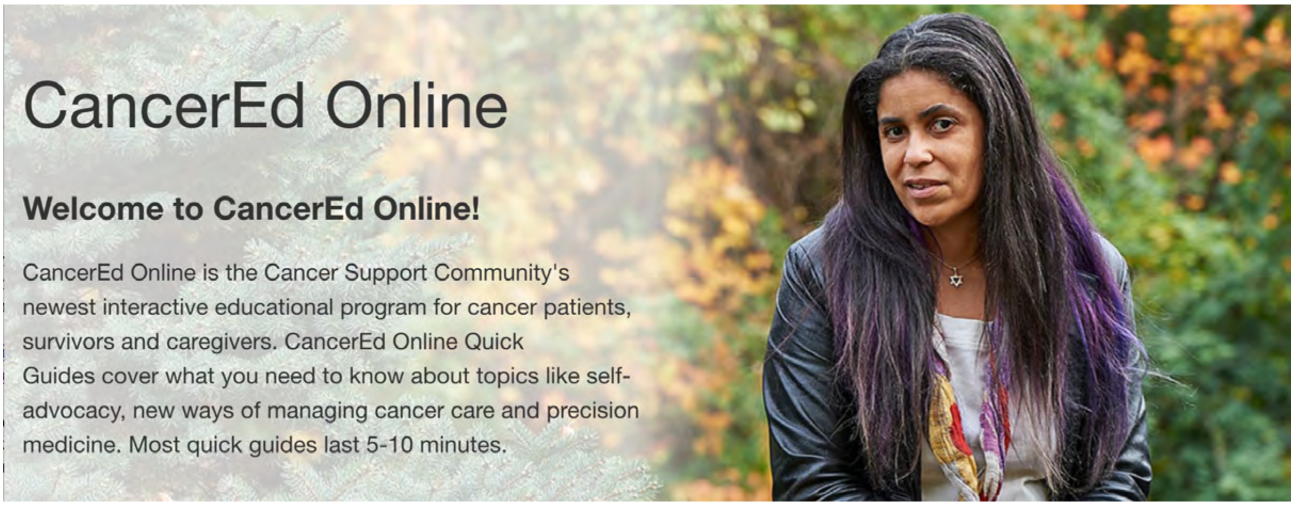
In 2018, we added to our collection of patient-centered radio shows, podcasts and videos with new content focusing on such issues as working with your medical team and the latest advances in immunology.

Kidney Cancer. Treatment for Stage 4 (Metastatic)

CAR T Cell Therapy Quick Guide

Join host Kim Thiboldeaux, CEO of the Cancer Support Community, for a weekly radio broadcast empowering listeners to live well with cancer.

We also introduced **CancerEd Online**, a web channel featuring short, interactive videos covering what patients need to know about self-advocacy, new ways of managing cancer care, precision medicine, and other topics.



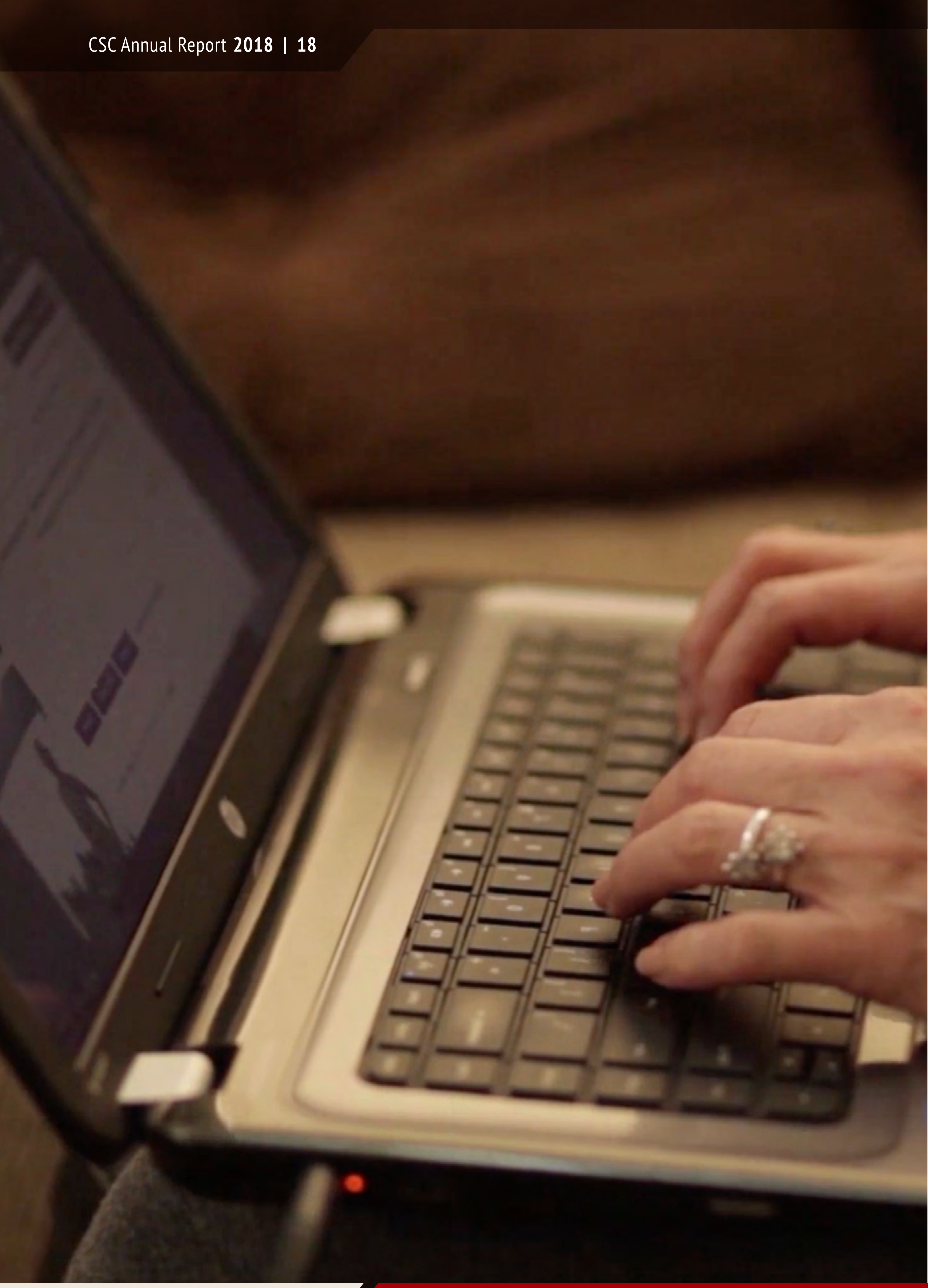
CancerEd Online

Welcome to CancerEd Online!

CancerEd Online is the Cancer Support Community's newest interactive educational program for cancer patients, survivors and caregivers. CancerEd Online Quick Guides cover what you need to know about topics like self-advocacy, new ways of managing cancer care and precision medicine. Most quick guides last 5-10 minutes.

I was diagnosed with metastatic breast cancer four years ago. I said, “I can take breast cancer, but if it’s spread, I won’t be able to take that.” The news was devastating that it had spread. **If I were to give someone advice today, I think it would be three things: support, support, support.** And like this place here, I started to get involved with some of the activities they have here, and those kind of things **have made a world of difference for my life in general, to feel a part of something and to know that you can ask questions** to people and not think that you’re dumb. And my nurse navigator was key to my **experience of feeling supported** because she was someone I really trusted. I knew she had my best interest in mind.

–Mary Lou Schafer,
Philadelphia, PA



MYLIFELINE & DIGITAL SUPPORT: **BROADENING OUR REACH**

SINCE THE MERGER LAST YEAR OF MYLIFELINE AND CSC, PATIENTS AND FAMILIES HAVE BENEFITED IN IMPORTANT WAYS.

Our annual analytics tell the story:

33K+	NUMBER OF ACTIVE USERS ON MLL ANNUALLY
115%	INCREASE IN THE NUMBER OF NEW PATIENTS USING MLL IN 2018
69%	INCREASE IN MLL WEBPAGE VIEWS IN 2018

MLL CUSTOMER SATISFACTION RATING

98%

MyLifeLine (MLL) community members have access to CSC's life-enhancing programs and services, including an ever-evolving library of multi-media educational content, real-time support and navigation via the Cancer Support Helpline, and the affiliate network's support groups and classes.

Additionally, people with cancer, their families, and caregivers can join MLL's community and take advantage of its convenient platform and resources to connect with their own friends and family around the world.

CSC GOES WEST

Thanks to the generous financial support of the Barbara Bradley Baekgaard Family Foundation, a partnership with the Rocky Mountain Cancer Center (RMCC) makes CSC's comprehensive programs, services, and support available to anyone in need throughout Colorado.

CSC and RMCC leaders made the announcement on July 13 at the Colorado State Capitol where Lt. Gov. Donna Lynne read a proclamation commemorating Colorado Cancer Caregivers Day.

> We share our story so that other families facing a cancer diagnosis know that you **do not have to endure this experience alone**. We believe in partnerships that enhance services for patients and caregivers, which is why we are thrilled by the connections between MyLifeLine, RMCC, and CSC—all of which played important roles in our journey.
>
> *–Britton and Jen Thomas (with their daughter, pictured in photo beside Lt. Gov. Lynne)*

Lt. Governor Lynne joins leaders from CSC and RMCC in proclaiming Colorado Cancer Caregivers Day.

RESEARCH & TRAINING INSTITUTE: PERSONALIZING THE EXPERIENCE

BEHIND EVERY DIAGNOSIS IS A REAL PERSON. A FAMILY. AND A TEAM OF CAREGIVERS INVESTED IN HIS OR HER SURVIVAL. THE RESEARCH AND TRAINING INSTITUTE SERVES AS A BRIDGE BETWEEN THESE COMMUNITIES BY AMPLIFYING AND DOCUMENTING THE REAL-LIFE CONCERNS OF PATIENTS— THEIR STATE OF MIND, THEIR TREATMENT PREFERENCES, AND WHAT MATTERS MOST.

Findings from our two flagship research programs—the Cancer Experience Registry® (measuring the patient experience, patient attitudes, preferences, and barriers) and the CancerSupportSource (measuring cancer-related distress) are shared with a variety of audiences— our affiliates to help them develop new or refine existing program and service offerings; CSC's Cancer Policy Institute to inform policy decision making, and health care providers and other stakeholders in order to enhance patient communication and understanding of their experience.

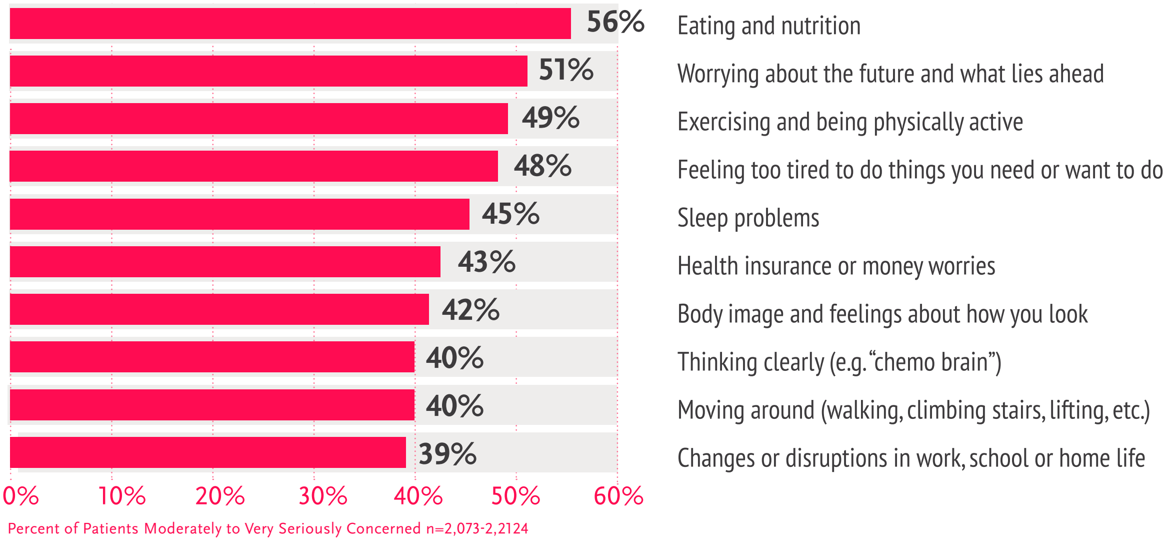
CANCER EXPERIENCE REGISTRY

The Cancer Experience Registry is a research study that collects valuable data on the patient experience from cancer survivors and caregivers. Our survey focuses on communication challenges with the health care team about diagnosis, treatment, and survivorship; the effects of cancer on quality of life; the financial burden of cancer; and how to best meet the psychosocial needs of patients and caregivers.

13,500
REGISTRANTS

As of this year, 13,500 registrants have participated in the CER. And in 2018, we added surveys to more precisely concentrate on twelve additional diagnosis-specific specialities.

TOP 10 CONCERNS ACROSS REGISTRY PARTICIPANTS



Source: Cancer Experience Registry

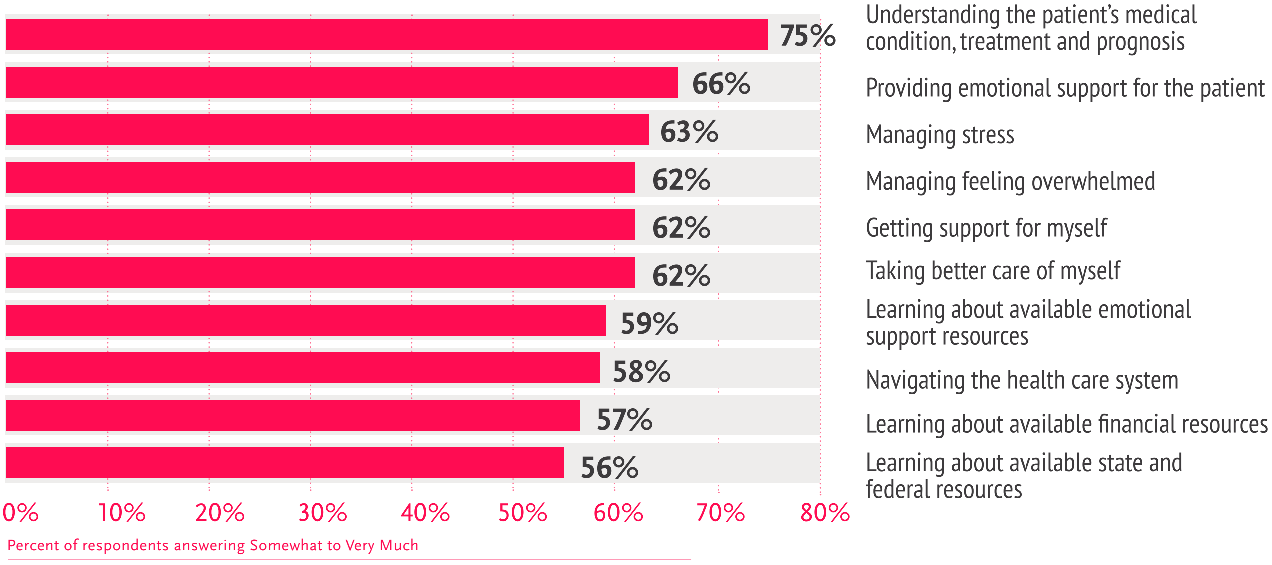
Cancer **clinical trials have historically failed** to adequately describe the patient experience of illness. Consequently, clinicians often lack vital information to guide conversations with their patients about what to expect from treatment, particularly across different regimens. **The Cancer Experience Registry is helping to enhance our understanding of patients' lived experiences with cancer,** and this is only becoming more important as treatments are increasingly successful. It's a critically important initiative that is helping to plug large gaps in our understanding.

—Dr. Thomas LeBlanc,
Associate Professor of Medicine,
Member of the Duke Cancer Institute
Advisor to the Cancer Experience Registry

CANCER SUPPORT SOURCE℠

CSS is a distress screening, referral, and follow-up program used at CSC affiliates and hospitals nationwide. It evaluates patient and caregiver response to a range of emotional, physical and psychosocial concerns and can also be used to identify those at risk for significant levels of anxiety and depression. Like the Registry, this evidence-based tool provides valuable insights into what programs/services can be developed to support not just patients, but families and caregivers whose stresses and contributions are often unrecognized and poorly managed.

CAREGIVERS WANT HELP WITH...



Source: CancerSupportSource


Tyice Wright, Warner Robins, GA

When Dave was diagnosed with oral squamous cell carcinoma, Thea dedicated herself to his recovery. “Dave is my family,” she explained. “I’ve got to keep him around.” Surgery and radiation caused severe side effects, but **Thea was there for him at every step of the way.** She watched the nurses to learn how to care for Dave and spoke up when she had concerns. Eating was especially tough so Thea learned to prepare meals he could eat. **When stress took a toll on Thea, Dave helped her find the support she needed to stay strong.** “We take turns taking care of each other,” he said.

–Dave and Thea Roff, Wilmington, DE

Felicia Johnson and Vicki Lee, Philadelphia, PA

STRATEGIC INITIATIVES: FROM DATA TO PROGRAM DEVELOPMENT

EVERY PROGRAM AND SERVICE PROVIDED BY CSC IS EVIDENCE-BASED AND DESIGNED TO BETTER RESPOND TO VERY REAL NEEDS. FROM EXPANDING OUR NETWORK OF HEALTH PARTNERSHIPS TO DEVELOPING DIAGNOSIS-SPECIFIC WEB PLATFORMS, WE SERVE PATIENTS AND CAREGIVERS WITH SCIENTIFICALLY VALIDATED EDUCATIONAL MATERIALS AND OPPORTUNITIES FOR EMOTIONAL SUPPORT AND COMMUNITY BUILDING.

A PIONEERING PARTNERSHIP WITH THE NAVAJO NATION

The Cancer Moonshoot Initiative, introduced by President Obama in his last State of the Union address, created the opportunity that connected CSC with leaders serving patients on the Navajo Nation. That collaboration continued after the Biden Cancer Initiative, founded by Vice President Joe Biden and Dr. Jill Biden, launched in 2017.

The centerpiece of this program is the partnership between CSC and the Tuba City Regional Health Care Corporation (TCRHCC), a nonprofit delivering health care to the Navajo, Hopi, and Southern San Juan Paiute residents on the Navajo Nation. With the generous support of Eisai and the Barbara Bradley Baekgaard Family Foundation, we established the first psychosocial support program for cancer patients on an American Indian reservation. We are working with TCHRCC leadership to ensure that CSC's culturally adapted program model becomes an integral component of care for patients on the Navajo Nation.

CSC accompanying two TCRHCC public health nurses on a wellness check on the Navajo Nation

BRINGING CSC CARE TO NEW COMMUNITIES

The Barbara Bradley Baekgaard Family Foundation has also underwritten our efforts to expand CSC health care partnerships to new areas of the country so we can provide programs and services to more cancer patients and their families in under-served or rural communities. This innovative model seeks to offer CSC's programs through six new health care partnerships, including Rocky Mountain Cancer Centers (CO), Tuba City (AZ), Kona Community Hospital (HI), Gettysburg Cancer Center (PA), Northwest Medical Specialties (WA), and Mosaic Life Care (MO).

IMMUNOTHERAPY & ME

Immunotherapy generates more traffic to our website than any other topic. Responding to patient demand, we developed immunotherapyandme.org, a web platform that empowers patients to take an active role in their care. By tracking symptoms and side effects with an app and the CSS distress tool, care providers can more immediately address patient concerns with personalized educational materials, medical staff intervention, or referral to the Cancer Support Helpline. Currently, CSC is partnering with nine oncology practices for this pilot in Washington, Colorado, Ohio, New York, Tennessee, and Mississippi.

—Mary Lou Schafer,
Philadelphia, PA

immunotherapy & me

A PROGRAM *of the* CANCER SUPPORT COMMUNITY

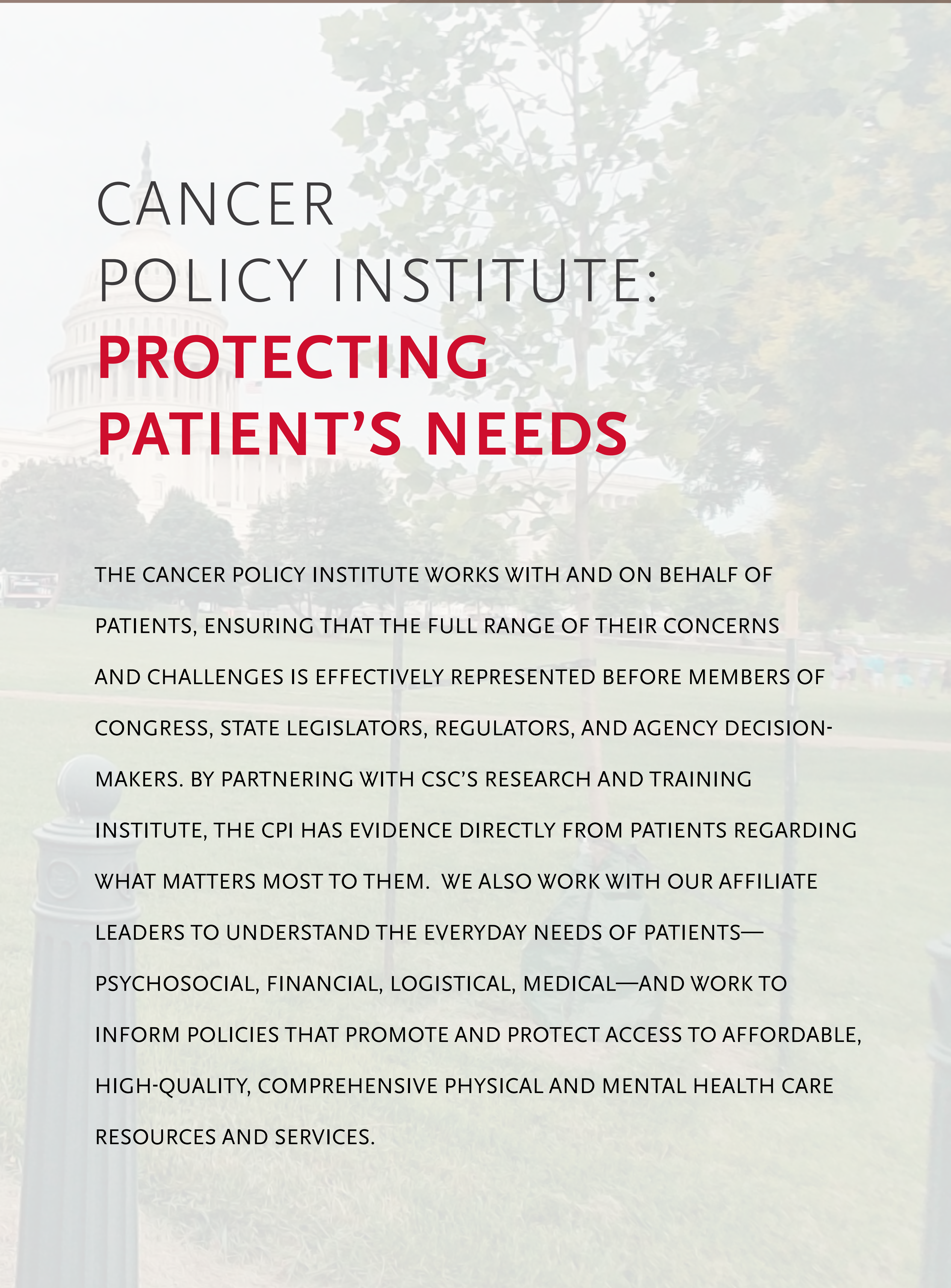
Welcome Packet

CANCER SUPPORT COMMUNITY

CANCER SUPPORT HELPLINE 833-442-8847

Immunotherapy & Me is a support program developed by the Cancer Support Community. This program does not replace your health care team or medical treatment. Do not make any changes to your treatment routine without first consulting your health care team. **If you are experiencing a medical emergency, call 911 or contact your health care team right away.**

Sandy Obodzinski, President and CEO, Gilda's Club Middle Tennessee, advocates for patients on Capitol Hill.



CANCER POLICY INSTITUTE: PROTECTING PATIENT'S NEEDS

THE CANCER POLICY INSTITUTE WORKS WITH AND ON BEHALF OF PATIENTS, ENSURING THAT THE FULL RANGE OF THEIR CONCERNS AND CHALLENGES IS EFFECTIVELY REPRESENTED BEFORE MEMBERS OF CONGRESS, STATE LEGISLATORS, REGULATORS, AND AGENCY DECISION-MAKERS. BY PARTNERING WITH CSC'S RESEARCH AND TRAINING INSTITUTE, THE CPI HAS EVIDENCE DIRECTLY FROM PATIENTS REGARDING WHAT MATTERS MOST TO THEM. WE ALSO WORK WITH OUR AFFILIATE LEADERS TO UNDERSTAND THE EVERYDAY NEEDS OF PATIENTS—PSYCHOSOCIAL, FINANCIAL, LOGISTICAL, MEDICAL—AND WORK TO INFORM POLICIES THAT PROMOTE AND PROTECT ACCESS TO AFFORDABLE, HIGH-QUALITY, COMPREHENSIVE PHYSICAL AND MENTAL HEALTH CARE RESOURCES AND SERVICES.

GRASSROOTS ENGAGEMENT

This year, we leveraged the power of social media to connect, inform, and educate greater numbers of advocates and policy makers, including:

@CSCCancerPolicy, our Twitter feed on the latest policy updates and advocacy tips

The Cancer Policy Institute Newsletter, covering patient issues, CSC research and CPI blog posts

Grassroots advocacy network: training, and organizing for our affiliates and thousands of patient partners nationwide

Cancer Policy Institute
@CSCCancerPolicy

Cancer Policy Institute (CPI) at the @CancerSupportHQ works to advance the mandate that comprehensive, quality cancer care includes social and emotional

Cancer Policy Institute Newsletter

April 2018

Dear [first-name],

As millions of people do each year in Washington, DC, I was recently walking through our beautiful cherry blossoms which bound the Tidal Basin. Surrounded by the stately memorials —Lincoln, Washington, Jefferson, FDR—I am always particularly struck by the Martin Luther King Jr. memorial. Open to the public since 2011, this stunning structure is the first memorial on the National Mall honoring an African American. Dr. King was only the fourth non-President to receive the honor. If you've visited this memorial you know that Dr. King's "Stone of Hope" is surrounded by his most famous quotes. As I was reading them, I realized that one of my favorite quotes was not included—and I immediately thought of the opportunity to share it with my fellow advocates: "Of all the forms of inequality, injustice in health care is the most shocking and inhumane."

Affiliate of the month: highlighting an individual active in his/her community.

Affiliate Capitol Hill Days: On June 13, 2018, CSC Affiliate leaders held dozens of meetings in Washington, DC with their members of Congress and staff to share more about the Cancer Support Community and Gilda's Club and to ask for their legislators' support of our work to include patient experience metrics into clinical trials.

I am a 3-time cancer survivor, diagnosed with osteosarcoma at 21, melanoma at 28 and breast cancer at 43. Being diagnosed with cancer at 21, three months shy of graduating from college, was life-changing. And while cancer definitely doesn't define me, it played an integral part of leading me on my life's path.

I was working for a CSC affiliate when CSC decided to launch the policy side of the organization. I was thrilled! It's so important to showcase the impact of cancer on the emotional aspect of people's lives and **CSC is well positioned to be a leader in this.** I attended the first CSC advocacy day in Washington, D.C. and have been a grassroots advocate since then. **I'm proud of how far the advocacy program has come since its launch.**

–Heather Hall, Detroit, MI

KEY ISSUES ON THE STATE LEVEL

Our efforts in 2018 focused on overcoming these barriers to care:

ORAL PARITY

With the rising number of treatments offered in oral form, we advocated for legislation requiring insurers to cover oral cancer medication options “no less favorably” than intravenous options.

STEP THERAPY

We supported legislation that refines step therapy practices to ensure that they are driven by clinical data and include essential patient protections (e.g. fast-tracked exceptions and appeals processes).

STATE MEDICAID WAIVERS

With the expansion of Medicaid coverage, many states have already utilized Medicaid waivers to implement restrictions that create a more limited environment, leaving many vulnerable patients without access to care. The CPI monitors, comments on, and educates patients and lawmakers about the negative impact of these policies.

ADVOCACY ON THE FEDERAL LEVEL

The CPI supports patients and caregivers in the policy-making arena in a variety of ways and works to educate policy makers with comment letters, blog posts and articles on critical issues affecting the patient experience, health care reform, drug pricing, and the perceived value of treatments.

ADVOCACY, ENGAGEMENT, ACTION

12
PRESENTATIONS

ACADEMY OF ONCOLOGY NURSE AND PATIENT NAVIGATORS

ASSOCIATION FOR VALUE-BASED CANCER CARE

NATIONAL ASSOCIATION OF SOCIAL WORKERS

ASSOCIATION OF ONCOLOGY SOCIAL WORK

NATIONAL COMPREHENSIVE CANCER NETWORK

GENENTECH

FDA

WORLD CONGRESS

NATIONAL HEALTH COUNCIL

PREVENT CANCER FOUNDATION

AMGEN

BIOSIMILARS FORUM

22
BLOGS

4
PUBLICATIONS

AMERICAN JOURNAL OF MANAGED CARE

VALUE IN HEALTH

JOURNAL OF CLINICAL PATHWAYS

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Right to Try

Step Therapy

4
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ICER & VALUE

IPI AND PART D REGULATIONS

In 2018, we also conducted research on the cancer patient’s experience with a variety of policy topics such as Medicare Parts B and D, shared decision making, and value-based cancer care. These topics have major policy implications and impact the daily experiences of patients and their families.

FINANCIAL STATEMENTS

For the years ending December 31, 2018 and 2017*	2018	2017
REVENUES AND OTHER SUPPORT:		
Development income	$ 799,196	$ 444,906
Net investment gain/ (loss)	(95,804)	264,999
Service delivery:		
Program	1,086,656	1,599,595
Research and training	1,171,044	1,306,126
Events and special initiatives	1,078,370	1,495,711
Digital services and web	691,000	120,000
Education/Outreach	2,051,992	1,698,631
Policy/Advocacy	1,726,250	1,693,150
Special purpose funds	300,920	24,919
Affiliate activities	576,234	502,855
Communications	7,353	17,500
In-kind revenue	163,279	83,767
Miscellaneous income	4,931	99,563
PPS sales, net of direct costs of $98,456 **	328,609	5,096
MyLifeLine merger consideration***	511,271	-
Total revenues and support	10,401,301	9,356,818
EXPENSES:		
Program services	8,343,883	6,764,456
Management and general	637,585	513,944
Fundraising	916,639	993,932
Operating expenses: PPS	444,920	413,272
Total expenses	10,343,027	8,685,604
Change in net assets	**58,274**	**671,214**
Net assets at beginning of year	10,320,017	9,648,803
Net assets at end of year	$ 10,378,291	$ 10,320,017

Vivian (Caregiver) and Avi Tuchman, diagnosed with Multiple Mieloma.

Cancer Support Community is proud of its financial stewardship. **We use 85% of all dollars donated to us for programs and services.** We remain grateful to the thousands of individuals and organizations who choose to invest in CSC, making it possible for us and our network of affiliates and partners to **deliver more than $50 million annually in free services to people living with cancer and their loved ones.**

WE ARE HONORED TO RECEIVE THE HIGHEST RATINGS BY GUIDESTAR, USA; CHARITY NAVIGATOR; INDEPENDENT CHARITIES AND PHILANTHROPEDIA.

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*Draft audited statement as of May 22, 2019. Final audited statements will be available at www.cancersupportcommunity.org after June 30, 2019 and by request at 202-659-9709.

**Patient Planning Services (PPS) is a subsidiary controlled by CSC that licenses certain CSC products and services to hospitals and other external partners.

*** MyLifeLine officially merged with CSC on January 2, 2018. This consideration reflects CSC's assumption of MyLifeLine's assets and liabilities.

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