

Cancer Experience Registry: Cancer Experience Days and the Critical Role of Affiliates in Outreach

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The Cancer Experience Registry

- CSC established the Cancer Experience Registry as a community of people touched by cancer. The primary focus of the Registry is on collecting, analyzing and sharing information about the experience and needs of patients and their families throughout the cancer journey.
- The Registry reaches cancer patients and survivors across the country, engaging them to share their voice about issues identified by national advisors, including patient representatives, health care providers, advocates, industry representatives and researchers.
- The Registry is open to anyone with any diagnosis and as of December 2014 will include caregivers of patients or survivors of cancer. In addition, the Registry includes numerous sub-registries for those living with breast cancer, metastatic breast cancer, multiple myeloma and chronic myeloid leukemia. By December, three additional new sub-registries will be launched on a dynamic new platform: lung, melanoma and caregivers of multiple myeloma survivors. More sites will be added in 2015.
- Through the Registry we are able to:
 - Garner, analyze and disseminate insights and knowledge in order to positively impact each individual's cancer experience.
 - Help inform the nation's health care systems to respond to the needs of cancer survivors.
 - Provide valuable data and insight that can be used to support affiliate programming and development.

There are now over 7,300 cancer patients and survivors in the Cancer Experience Registry from over 35 countries and representing more than 40 cancer diagnoses. Our goal by the end of 2015 is to have at least 15,000 people living with cancer, survivors, and caregivers join the Registry. We need your help to reach this goal!

Elevating the Patient Voice: Cancer Experience Registry Index Report 2013-2014

Kelly D. Diagnosed with Triple Negative Breast Cancer 2011

"I didn't get involved with cancer— it got involved with me. I was living my life. The diagnosis almost took me down. I almost went over the deep end. The emotional support I got from the Cancer Support Community allowed me to draw positive energy from people who were going through what I was going through, and am still going through. It became a safe haven for me, a place filled with kindred spirits. I can't see how I could help someone else if I couldn't find the strength to help myself."



Lloyd K. Diagnosed with Lung Cancer 2012

"Before my diagnosis, I didn't know anything about cancer. Now, I have met so many people with so many different kinds of cancer experiences—and I really go back to the idea that no one should ever have to go through cancer alone. I have gained so much from the Cancer Support Community's mindfulness program. It's something that will be with me all my life. I don't understand why more men don't get involved in support programs. Maybe it's just the nature of the beast, but you end up getting support in areas you might not even be aware exist."



2015 Cancer Experience Days Initiative Overview

Goal

- To expand the Registry to reach 15,000 people living with cancer, including survivors and caregivers that represent the diverse communities across our affiliate network.

Description

- **February 8 – 22, 2015** have been designated for a campaign to raise awareness and increase outreach and recruitment for the Registry across the affiliate network.

Affiliate Role

- Host at least one event to promote awareness of the Registry through the local affiliate networks.
- Help recruit new members of the Cancer Experience Registry during the two week time period in mid-February.

Our Role

The Cancer Support Community's Research & Training Institute will:

- Provide a recruitment goal for each affiliate, based on membership size and operating budget (as available in ADAPT).
- Provide a toolkit with outreach and awareness materials, including email template language and a flyer.
- Keep track of new registrants and which affiliate directed them to the Registry.
- Award prizes to affiliates upon meeting individual goals.

Incentives and Prizes

- Affiliates who schedule a social event to raise awareness and conduct outreach for recruitment through the Registry will receive \$100 to cover costs.
- Affiliates who DOUBLE their recruitment goal will receive an extra \$150.
- **Tier One:** recruitment goal = 15; double goal = 30
Budget (\$340,000-\$684,300)
- **Tier Two:** recruitment goal = 25; double goal = 50
Budget (\$714,500-\$912,300)
- **Tier Three:** recruitment goal = 35; double goal = 70
Budget (\$940,000-\$1,667,700)

Recruitment Tips

- Make an Announcement
- Post it to Your Website
- Use Social Media
- Include it in Correspondence
- Say it With a Flyer
- Have a Conversation
- Be Creative
- Engage the target cancer communities



Cancer Experience Days Toolkit

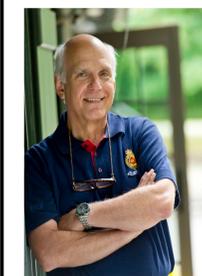
- A letter to community partners (hospitals, cancer centers) explaining the Registry and the benefits to patients and partners through participation
- A PowerPoint with key messages and findings
- Social media messaging
- Email and newsletter templates
- Flyer

Conclusion and Future Directions

- **Goal:** By the end of 2015, at least 15,000 people living with cancer, survivors, and caregivers will have joined the Registry. We need your help to reach this goal.
- **Next steps:** In October 2015, the second Index Report will be published highlighting findings from 2014 and 2015, including new sub-registries.

Value of the Cancer Experience Registry

- The Registry data will provide value-added information to affiliates and their partners to help build more effective relationships. RTI will provide to affiliates who participate in Cancer Experience Days segmented data to better understand the needs of their community.
- The Registry index and report helps affiliates link to the programs and services they provide locally.
- A key goal is for CSC to become a "go-to" resource for expertise on the patient experience.



 **CANCER EXPERIENCE
REGISTRY**

Anyone who has ever been diagnosed with cancer of any type can join the Cancer Experience Registry at:
www.CancerExperienceRegistry.org