

pink  lemonade project®



**Susan Stearns, CEO**

at 7<sup>th</sup> Annual Knight Cancer Network Symposium

March 3, 2023



**Mission: To Educate, Empower, and Support all communities affected by breast cancer.**

**Serve: All of Oregon and Southwest Washington**



## Early History



- Founded in 2010 by Dr. Allen and Cassie Gabriel, two Vancouver-based physicians
- Aimed to address psychological and emotional needs of breast cancer patients following diagnosis and treatment
- Early on worked with Susan Hedlund, OHSU, LCSW to:
  - Develop three-day retreat for BC patients a year out after treatment
  - Train a cohort of peer mentors to match with newer BC patients



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pink link™  
*linking those affected by  
breast cancer with one another*

Jill's  
bookbank™

## Over Next Few Years:

Holiday  
Glow™  
pink lemonade project®

- Added educational series which included medical topics and community building events
- A bequest started a book bank for children and families to learn about a cancer diagnosis
- Early efforts to develop financial aid programs that address quality of life needs, and improve the holidays for breast cancer patients





## On March 2, 2020

- Susan Stearns was hired as first breast cancer patient on staff of PLP
- Background included many decades of healthcare reform policy and community-level systems change work
- Personal commitment to convene the myriad of local breast cancer groups and improve communication and coordination of community organizations across the region

Personal thank you to Dr. Jacqueline Vuky at OHSU Knight Cancer Institute and Dr. Nathalie Johnson at Legacy 😊





## Year One of Pandemic

- Pink Lemonade Project shifted programming to virtual immediately as healthcare system canceled all cancer support programming
- Activated peer mentors to offer daily support groups for 6 weeks
- By end of 2020, raised and distributed nearly \$125,000 as direct cash assistance to breast cancer patients in treatment
- Convened local breast cancer community organizations



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## Then, in mid-January 2021

- Susan G Komen Oregon SW Washington announced required closure on 3/31/21 as part of national Komen restructuring
- Pink Lemonade Project was approached to continue MBC Dinner Series and Treatment Access Program (TAP)
- By accepting TAP, PLP's geographic area expanded to serve all of Oregon and SW Washington



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## Context for CPP Application/Community Need

- Healthcare systems' cancer support programming not back to pre-COVID levels
- Breast cancer patients in treatment had to look elsewhere for support
- COVID strained healthcare systems and staff, and resources were out of date
- Local Komen's departure left large gap across Oregon and SW WA
- Breast cancer patients across the region have varied experiences of receiving cancer support information depending on place of care







## Pink Lemonade Project's Tier 2 Grant Award

- Developing a community system of care for individuals diagnosed with breast cancer across Oregon
- August 2021-June 2022



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## Tier 2 Grant Goals/Objectives

- Update community resources and peer supports for the breast cancer community using collaboration and patient input
- Serve as neutral convener and invite regional health systems share patient binders to develop and distribute common, community resources
- Train healthcare partners across Oregon about Pink Lemonade Project's programs and community resources—esp. financial aid
- Test whether patients who request transportation assistance desire more supports during treatment, recovery, survivorship etc.



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## Target Audiences

- Breast cancer coalition organizations which expanded to include new partner organizations like those that took other Komen affiliate's programs, and community organizations that best serve more people of color/communities
- Breast cancer patients, survivors, those living with metastatic breast cancer
- Healthcare partners across Oregon (and SW Washington)
- Treatment Access Program patients across Oregon



## Grant Results

- Obj 1: Average of 10 Portland metro area BC organizations attended the 4 quarterly meetings during grant period
- Obj 2: Binders collected from Compass Oncology, Kaiser Permanente, Legacy, OHSU, PeaceHealth Southwest Medical Center and Providence
  - 11 patients reviewed including native Spanish speaker and 3 w/MBC
  - Also developed list of ideal topics for new patient binders
  - 44 local and national resources compiled and distributed
  - 67 health professionals from 15 cancer centers were trained
- Obj 3: Of 126 TAP recipients, only 33 completed survey, and only 7 contacts made about additional resources



## Grant Work Products: Standard Community and National Resource Guide

**Pink Sistas**

**Breast Friends**  
• Various peer support groups for breast cancer survivors and forever fighters  
• Brave & Beautiful: professional portraits

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**Community Resources for Breast Cancer Patients**  
*Please note that a best faith effort has been made to provide accurate information for each organization.*

If you are aware of other local or national resources that could be added to this list, please contact us at [programs@pinklemonadeproject.org](mailto:programs@pinklemonadeproject.org).

**In the Portland / Vancouver Metro Areas:**

**Pink Lemonade Project** (visit [pinklemonadeproject.org](http://pinklemonadeproject.org) for specific program eligibility)

- Jill's Book Bank: free books for children, families, and adults to discuss a breast cancer diagnosis
- Peer Support groups: Zest for those diagnosed at a younger age; Limoncello for women of all ages
- Pink Peers Mentor Program: trained peer mentors
- Pink Link: education, craft, and wellness activities
- Pink Practicalities and Holiday Glow: financial assistance
- Revive Retreats: oncology social worker-led retreats for those at least one year past treatment
- Treatment Access Program: financial aid for those with travel needs to treatment
- Various support groups, facilitated by oncology social workers, for breast cancer survivors and forever fighters, including one in Spanish
- Virtually Pink: online education, craft, and wellness events; view past events at: [bit.ly/VirtuallyPink](https://bit.ly/VirtuallyPink)

(360) 952-3814  
[programs@pinklemonadeproject.org](mailto:programs@pinklemonadeproject.org)  
[pinklemonadeproject.org](http://pinklemonadeproject.org)

**21 Info**  
• Help people across Oregon & SW Washington identify, navigate, and connect with local resources

Dial 2-1-1  
21 Info.org

**Asian Cancer Resource & Support Services Center** (a division of Asian Health & Service Center)

- Community-based breast cancer patient navigation that is culturally and linguistically specific; Vietnamese, Cantonese, Mandarin, and Korean
- Emotional support through counseling, peer support, and support groups
- Garden of Reflection
- Health talks, patient education, resource library

(971) 262-9600  
[acrss.ahscpxd.org](http://acrss.ahscpxd.org)

**Be Inspired to Grow: Health & Wellness Coaching**  
• Katrin Fink, Mayo Clinic Certified Wellness Coach & Board-Certified Health and Wellness Coach, supports cancer survivors in making positive lifestyle and behavior changes that promote health and wellbeing

(503) 686-0379  
[beinspiredtogrow.com](http://beinspiredtogrow.com)

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## Grant Work Products: Feedback to Health Systems On Patient Binders from Patient Perspective

**Health Topics Inclusion Survey**

Reviewer information (optional):  
Of the following health topics please mark if you would like to see it included in a treatment binder or not:

Health Topics	Don't Include	No Opinion	Important to Include
<b>What is Breast Cancer:</b>			xxxxxxx
Breast Screening	xxx	x	xxxxxxxxx
Types of Breast Cancers			xxxxxxxxx
Types of Surgeries (lumpectomy, mastectomy, etc.)		xx	xxxxxxxxx
Plastic Surgery			xxxxxxxxx
Pathology Reports		x	xxxxxxxxx
Blood Work and Labs	x		xxxxxxxxx
<b>Treatments</b>			xxxxxxxxx
Chemotherapy			xxxxxxxxx
Chemotherapy Side Effects		xx	xxxxxxxxx
Hormonal Therapy		xx	xxxxxxxxx
HER2 Directed Therapy	xx		xxxxxxxxx
Line Care			xxxxxxxxx
Radiation		x	xxxxxxxxx
Medication Information		xxx	xxxxxxxxx
Integrative Medicine			xxxxxxxxx
<b>Post Cancer Treatment Care</b>			xxxxxxxxx
Nutrition			xxxxxxxxx
Self-care after Treatment		x	xxxxxxxxx
Coping and Talking About your Cancer			xxxxxxxxx
Physical Therapy after Mastectomies			xxxxxxxxx
Children and their Feelings	x	xx	xxxxxxxxx
<b>After Treatment-Survivorship, Living with MBC</b>			xxxxxxxxx
Table of Content, Tabs, Glossary		x	xxxxxxxxx
Glossary of terms and acronyms			xxxxx
<b>Legal Documents/Forms</b>			xxxxx
Advance Directives	x	xxxxx	xxxxx
Patient Bill of Rights	x	xxxxx	xxxxx
Clinical Research		xxx	xxxxx
Financial Assistance Information/Resources	x		xxxxx
<b>Local Resources</b>			xxxxxxxxx
Prostheses and Lingerie Information		x	xxxxxxxxx
Local Breast Cancer Organizations			xxxxxxxxx
Local Support Groups		xxxxx	xxxxx
Fertility Preservation	x	xxxxx	xx
Smoking Cessation	xxxxx		xxxxxxxxx
Transportation Resources	x	xx	xxxxxxxxx
Wig Specialists			xxxxxxxxx
<b>National Resources</b>			xxxxxxxxx
Breast Cancer Websites		xxx	xxxxxxxxx
Advocacy Groups		xxxxx	xxxxxxxxx
Reading Suggestions		x	xxxxxxxxx
Support Groups	xxxxx		xxxxx
Stop Smoking Resources			xxxxxxxxx
<b>Healthcare Team</b>			xxxxxxxxx
Breast Cancer Specialists Names and #s	x	xxx	xxxxxxxxx
Social workers Info/Names and #s	x	x	xxxxxxxxx
Nurse Navigators info/Names and #s	x	x	xxxxxxxxx
Survivorship team name and #s	x	x	xxxxxxxxx
Financial Counselors names and #s		xxx	xxxxxxxxx
General Phone Numbers to Depts.			xxxxxxxxx
<b>COMMENTS</b>			
Blank page for patient to add phone #s			
Blank page for notes at doctor's appt.			
Suggested questions to ask with new diagnosis			
Need to be careful about overwhelming newly diagnosed people with DCIS with all the worst case scenario information - some of the less commonly needed info could be given when it is needed for more severe cases.			
The Health Care Team is hard to keep up-to-date. Therefore, give current info as needed.			
"Include MBC! It's absence makes me think: 1) It doesn't exist or 2) It's too scary to talk about. Not helpful and a missed opportunity.			
"Make it easy for us, please!" (referring to the Health Care Team section.)			
Add genetic and sexuality with Local Resources.			
"I'm a 'the more the info the better' person, but I recognize that can be overwhelming."			
Add more about when/why to get genetic testing after diagnosis.			
Reviewer 11 wanted Healthcare Team info mention for each hospital or medical provider if we did one binder.			

**2022 Pink Lemonade Project Review of Local Breast Cancer Center Patient Binders**

Health system binder being reviewed: OHSU (2018)

How would you rate the content of the following binder:

	Very helpful	Somewhat helpful	Neutral	Not very helpful	Not at all helpful	NA/Missing	Comments
Overall Organization of binder:	9	0	1	0	0	0	*Lots and lots of tabs (but to me) not in a helpful/logical order *Dividers, tabs, etc.
General information on breast cancer/diagnosis:	2	1	1	1	1	3	*Doesn't seem to have anything specific to breast cancer
Information related to treatment such as:							
Surgery:	2	4	2	0	1	2	
Chemotherapy:	9	2	0	0	0	0	
Side Effects and Management of Chemo:	9	1	1	0	0	0	*basic side effects are covered but too text heavy, hard to find things
Line Care:	4	2	1	1	0	1	
Radiation:	8	2	0	0	1	0	
Medications:	5	4	0	0	1	0	
Information related to:							
Recovery:	2	2	1	0	0	1	
Survivorship:	2	1	1	0	0	5	
Advanced Diagnosis/MBC:	0	0	1	0	2	3	
Community Resources:	3	3	2	1	0	10	*Needs updated to include breast cancer
Integrative Services:	1	5	0	0	0	4	*somewhat mentioned
Participants found this additional information in your binder and rated it:							
Financial support	0	0	0	0	0	1	
Palliative care	0	0	0	0	0	1	
Advance Directive	0	0	0	0	0	1	
Life issues	1	0	0	0	0	1	
Glossary	1	0	0	0	0	0	
Complementary alternative therapies and herbal	0	1	0	0	0	0	



## Grant Challenges

- Pandemic extended longer than ever imagined so hard to get involvement from oncology social workers and navigators
- Significant turnover of healthcare staff across Oregon and SW Washington made contact lists out of date.
- Pink Lemonade Project had difficulty tracking Treatment Access Program patients as patient contact information goes to 211info, the TAP program administrator. More work needed.
- Provided detailed feedback to each health system on patient binder but not enough time to followup directly on how implemented



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## Next Steps

- PLP will continue updating contact lists to share community resources
- PLP is completing a full HIPAA audit and exploring becoming fully HIPAA compliant entity so can (1) improve patient communication with healthcare system and (2) bring TAP in-house
- Need to set meetings with each health system to review patient feedback on new patient binders and keep distributing updated community resource guide.
- Develop next iteration of community resource guide to serve all of Oregon and to better incorporate more culturally competent resources





## Project Thank You's

- **Health and Human Service Partners:** 211 info, Compass Oncology, Kaiser Permanente, Legacy Health System, OHSU, PeaceHealth SW Medical Center, and Providence Health System
- **Funders:** Carpenter Foundation, Cow Creek Umpqua Indian Foundation, Marie Lamfrom Foundation, MJ Murdock Charitable Trust, Natrelle, PacificSource Foundation, The Renaissance Foundation, Weyerhaeuser Community Fund and other individual donors
- San Antonio Breast Cancer Symposium for poster session opportunity
- **And, of course, The Knight Cancer Institute CPP Team!**



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## Thank you, Local Breast Cancer Coalition Partners



# Questions?



# Thank you!

Susan Stearns

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360-952-3814 ext. 3