



LIVING BEYOND  
BREAST CANCER®

# Thriving Together

2025 CONFERENCE ON METASTATIC BREAST  
CANCER

---

# Insurance & personalized medicine: Accessing what you need

LBBC Thriving Together:  
2025 Conference on  
Metastatic Breast Cancer  
March 8, 2024

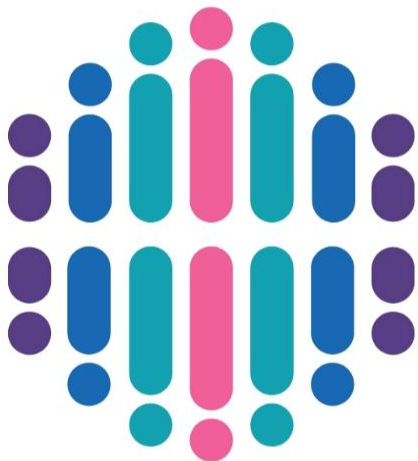
Lisa Schlager  
Vice President, Public Policy  
FORCE: Facing Our Risk of Cancer Empowered



LIVING BEYOND  
BREAST CANCER®



# FORCE Programs



## Support

- Personalized Peer Support
- Virtual Support Groups
- Private Facebook Group and Message Boards
- Helpline

## Advocacy & Public Policy

- State & Federal Advocacy
- Insurance Coverage & Access to Care
- Genetic Privacy & Protections
- Drug/Medical Device Development & Safety

## Education

- Information on Genes & Hereditary Cancers
- XRAY – Behind the Cancer Headlines
- Educational Brochures & Decision Guides
- Expert Led Webinars and Videos

## Research

- Hereditary Cancer Research Recruitment
- Collaborations to Advance Research
- Research Advocate Training

# Costs of Cancer



Your costs depend on many things:

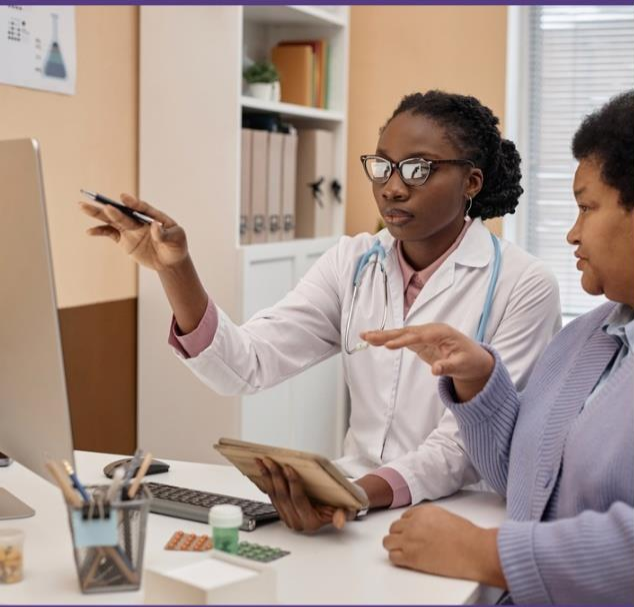
- Type of health insurance (if insured)
- Health plan specifics
  - deductible, copays, etc.
- Your income
- Treatment(s) chosen

# Costs of Cancer



## Other expenses:

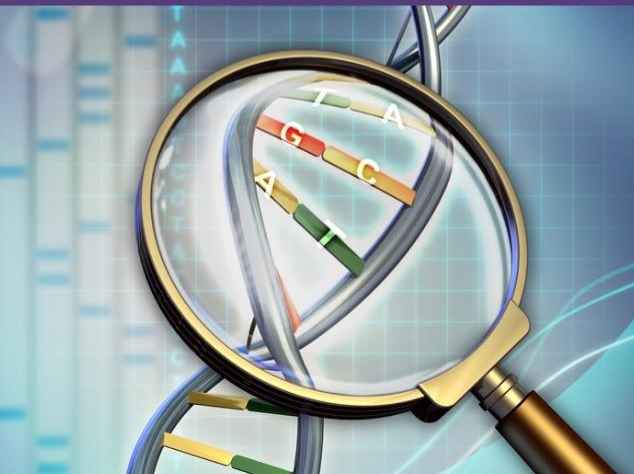
- Travel to/from treatment
  - Gas, parking, tolls, lodging
- Time off from work
- Treating side effects
  - wigs, scalp cooling, special diets
- Childcare and/or elder care
- Help with household tasks



# Personalized Medicine

Challenges “one-size-fits-all” approach

- ✔ Informs Medical Decisions
- ✔ Access Targeted Therapies
- ✔ Improved Treatment Efficacy
  - ✔ More effective therapies
  - ✔ Safer drugs (avoid predictable side effects)
- ✔ Reduced trial-and-error
  - ✔ wastes time
  - ✔ undermines care
  - ✔ inflates health care costs



# Types of Testing



## Hereditary Cancer

Uses blood or saliva to assess DNA and find gene mutations linked to an increased risk for hereditary cancer.



## Tumor/Biomarker

Analyzes tumor tissue to identify genetic changes, proteins, or other substances (biomarkers) that can provide information about a person's cancer .



## Liquid Biopsy

Detects signs of cancer in a blood sample by analyzing small pieces of tumor DNA (circulating tumor DNA - ctDNA) or cancer cells (circulating tumor cells - CTCs).

# Utilization Management

Aims to ensure that healthcare services are used appropriately, efficiently, and cost-effectively

## Assess medical necessity

Are proposed treatments, tests, or procedures medically necessary?

Do they align with evidence-based guidelines?

## Monitor care during treatment

Track patient progress and ensure services are being provided as intended.



## Review care after treatment

Evaluate outcomes of care and identify areas for future improvement.

# Utilization Management

Typically includes three main components:

## **Pre-authorization**

Obtain approval from health insurer before a specific drug, procedure, service, or device will be covered. Also known as: prior authorization or precertification

## **Concurrent review**

Monitoring care while it is happening to ensure appropriateness and avoid unnecessary expenses.

## **Retrospective review**

Examining care after it has been provided to identify potential issues and make adjustments.



# Benefit Managers



## Pharmacy Benefit Managers (PBMs)

- Middlemen between drug companies, insurers, and pharmacies
- Manage prescription drug benefits for health insurance plans, employers, and government programs
- Negotiate with drug manufacturers to develop plan's formulary
- Negotiate with pharmacies to develop plan's pharmacy network
- Influence formulary, drug tiering, and drug pricing



## Laboratory Benefit Managers

- Companies that manage lab benefits for health insurance plans
- Guide physicians towards clinically actionable tests and labs performing reliable testing
- May help labs identify appropriate CPT codes for reimbursement coverage.
- Aim to optimize test use and reduce healthcare costs by controlling payment for lab services

# Alternative Funding Programs (AFPs)



- Third-party companies that partner with employer-sponsored health plans
- Identify alternative sources for the health plan's specialty drug benefits
- Alternative sources may include:
  - Patient Assistance Programs (PAPs)
  - Copay Assistance Programs
  - Importation from International Pharmacies

# Step Therapy

## “Fail First” Protocol

Insurer denies coverage of a physician-prescribed medication until the patient tries one or more alternative treatments.

1

Take lower-cost medication, typically a generic drug or a preferred brand-name drug.

2

If first medication is not effective, patient can move to a more expensive medication.

3

Sometimes, there is third step, where patients can try an even more expensive/specialized medication.

# Clinical Trials

- Access to new agents and/or cutting-edge technology
- Contribute to scientific knowledge that may benefit you, your family and society
- Close health monitoring
- Expert medical care



# Expanded Access

And “Compassionate Use”



- With FDA oversight, allows patients access to investigational drugs, biologics, or medical devices
  - Treatment option for patients who have exhausted all available conventional therapies
- Right to Try
  - A separate legal pathway where patients can request access directly from a drug manufacturer (with minimal FDA involvement)
- Coverage with Evidence Development (CED)
  - Insurer (i.e. Medicare) agrees to pay for promising new technology or treatment under the condition that clinical data is collected
  - Goal is for data to help payer decide if a treatment is “reasonable and necessary” and determine how future coverage decisions are handled

# Expanded Access

And “Compassionate Use”



Make genetic counselors approved Medicare providers

- Access to Genetic Counselor Services Act -  
H.R. 3876 / S. 2323

# Expanded Access

And “Compassionate Use”



Cover prostate cancer screenings for men at increased risk with no patient cost-sharing

- PSA Screening for HIM Act - H.R. 1826 / S. 2821

# Appeal!

Many appeals are approved



Regulations issued by HHS, Labor, and the Treasury department standardize the internal and external appeals processes.

## Internal Appeal

- Some insurers have two levels of internal appeal

## External Appeal

- All states have an external appeals process that meets the consumer protection standards of the Affordable Care Act
- Medicare has an external appeal process as well

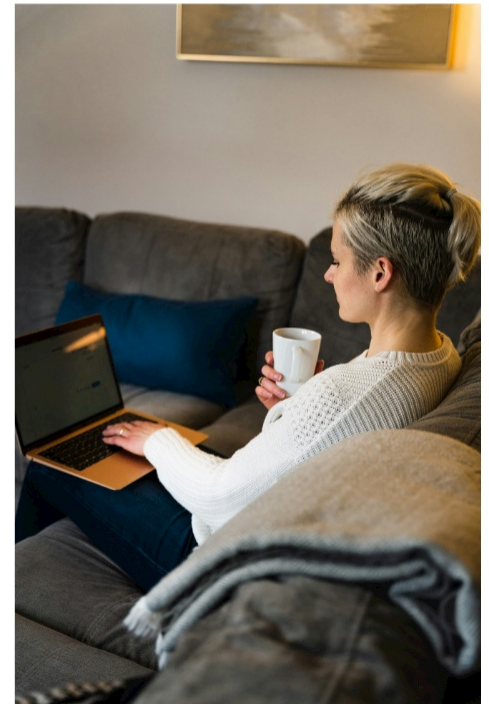
## Expedited Appeal

- Most health plans offer an expedited process where they respond within 72 hours of getting a qualifying appeal

# Resources

## Navigation & Legal Guidance

- **Patient Advocate Foundation** provides information on health insurance denials and appeals, and has case managers who can help you navigate insurance challenges. <https://www.patientadvocate.org/>
- **Triage Cancer** has extensive information on health insurance appeals and other useful cancer-related resources. <https://triagecancer.org/>
- **Medicare Rights Center** works to ensure access to affordable healthcare for Medicare beneficiaries. <https://www.medicarerights.org/about>
- **National Cancer Legal Services Network** promotes healthcare access and seeks to increase the availability of legal services for people affected by cancer. <https://legalhealth.org/nclsn/>
- **Cancer Legal Resource Center** - Guide to Navigating Health Insurance Appeals and other useful tools. <https://thedrlc.org/cancer/>



# Resources

## Cancer Care Grants & Financial Assistance



- **LBBC Fund** offers a one-time grant to help ease the financial stress of breast cancer - <https://www.lbbc.org/about-us/what-we-do/lbbc-fund>
- **FORCE Resource List** - <https://www.facingourrisk.org/support/find-financial-assistance/cancer-care>
- **Susan G. Komen** financial assistance program - <https://www.komen.org/financial-assistance-program/>
- **National Breast Cancer Foundation** patient relief program - <https://www.nationalbreastcancer.org/nbcf-programs/patient-relief-program/>
- **CancerCare** Co-Payment Assistance Foundation - <https://www.cancercare.org/copayfoundation>
- **Healthwell Foundation** fill insurance gaps by assisting with copays, premiums, deductibles and out-of-pocket expenses - <https://www.healthwellfoundation.org/>

# Resources



## Advanced Disease:

- **Angelmira's Center** for Women with Advanced Breast Cancer Foundation - <http://www.angelmira.org/>
- **Patient Advocate Foundation** Fund Supporting Stage III and Stage IV breast cancer patients - <https://www.patientadvocate.org/>

## Expanded Access:

- **The Reagan-Udall Foundation** Expanded Access Navigator (patients, caregivers, physicians, and pharmaceutical companies) - <https://navigator.reaganudall.org/>
- **FDA Project Facilitate** (for clinicians) - <https://www.fda.gov/about-fda/oncology-center-excellence/project-facilitate>

# Other Types of Assistance

- Pharmaceutical products/medications
- Laboratory services assistance programs
- Rent/mortgage
- Utilities
- Groceries
- Travel & lodging
- Fertility services
- Childcare
- Self-care items
- Housecleaning
- Prostheses
- Wigs





Facing Hereditary Cancer EMPOWERED

**Lisa Schlager**

Vice President, Public Policy

Email: [LisaS@facingourrisk.org](mailto:LisaS@facingourrisk.org)

Phone: 301-961-4956

LBBC Thriving Together:  
2025 Conference on Metastatic Breast Cancer

