



## **Imagine Session**

*Working towards a world without financial barriers  
for cancer patients and families.*

Family Reach presents:

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September 28, 2017

Event Report

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## Executive Summary

Cancer-Related Financial Toxicity: Over 73 percent of cancer patients experience some form of cancer-related financial toxicity (CRFT) every year, leading to financial insecurity, bankruptcy, poorer adherence to cancer treatment and, ultimately, a lower chance of survival. CRFT encompasses the full spectrum of financial hardships faced by patients and caregivers and occurs when out-of-pocket costs (e.g. travel, hotels, deductibles) are high relative to income, and when income is lost as treatment requires reduced work hours. Families report difficulty understanding how to anticipate out-of-pocket spending while managing inconsistent monthly expenses and income during this unexpected time in their lives. As a result, they make dangerous decisions that may lead to bankruptcy or poor health outcomes. In recent years, CRFT has made its way to the forefront of the oncology conversation as researchers invest in data.

Family Reach: Family Reach is a national organization alleviating the financial burden of cancer for patients and their families. Cancer cuts many household incomes in half as patients and caregivers put careers on hold during treatment. This loss of income forces families to make dangerous decisions - do they skip a chemo appointment to pay their mortgage? Through financial assistance and innovative financial interventions, we're empowering families with the tools and knowledge they need to keep a roof over their heads and maintain access to treatment, ultimately increasing their loved one's chances of survival. For more information visit [www.familyreach.org](http://www.familyreach.org).

Imagine Session, September 28, 2017: For the second year in a row, Family Reach united 70 business leaders from both the public and private sectors to raise awareness for CRFT and work together to develop solutions. Morning panel sessions were educational, including personal stories of CRFT, the current state of research and data around CRFT and how the healthcare system is currently addressing financial needs and barriers of patients and caregivers. The afternoon brainstorming activity led to the development of program and partnership concepts to address CRFT from a multitude of angles - transportation, food, housing and beyond - and fill the gaps that exist in a patient's financial journey.

Future Needs: The primary desires of cancer patients and their families struggling with CRFT include financial planning, mortgage forbearance during treatment, insurance navigation and increased awareness for CRFT earlier in the cancer journey.

Looking Ahead: Imagine Session Follow Up: As a follow up to the Imagine Session, Family Reach published a white paper summarizing key CRFT data presented during the event. This resource is being used by Imagine stakeholders to open doors with economists, researchers and policy makers to begin exploring future research and program opportunities. Family Reach will continue to lead this innovative collaboration with outside stakeholders to solve this national crisis on a broader scale, launching working committees to drive solutions forward. Discussion will continue through Imagine via a series of smaller events in 2018, and a third session planned for 2019, during which the organization will report back on progress and impact.

## Proceeding of the Event

**Moderator: Mario Muredda, President, Harrison & Star**

### Opening Session

#### ***Financial Barriers: The Patient & Caregiver Experience***

#### ***Panel Discussion***

#### Objectives:

Comprised of patients and caregivers, this panel provided an inside look at the financial struggles endured by families with cancer. Panelists were selected to share first-hand accounts on how and when cancer-related financial toxicity comes to life for families throughout their journey. What impacts a family's overall well-being the most during treatment? When do financial barriers pop up? What decisions are patients forced to make as a result of these barriers? Speakers included:

- Anabella Aspiras, caregiver to her mother (breast cancer)
- Leslie Longo, caregiver to her husband (Hodgkin's lymphoma)
- Michael Longo, patient (Hodgkin's lymphoma)
- Felix Modestin, caregiver to his son, Nicholas (acute lymphoblastic leukemia)
- Leslie, caregiver to her daughter, Ella (acute lymphoblastic leukemia)

#### Summary & Conclusions:

All panelists agreed that their first thoughts upon receiving their cancer diagnosis revolved around treatment options and length, the well-being of their family and life expectancy. As the journey progressed, each quickly faced the financial hurdles as a result of the diagnosis. The panel discussed:

- Loss of income
- Depleted savings
- Mounting credit card debt
- Added out-of-pocket costs

The group expressed feelings of isolation, fear, confusion and frustration spurred by lack of information and direct support surrounding CRFT upon diagnosis. Filling gaps in policy for cancer patients and families, hospital staffing (resource and insurance navigation) and financial planning were all identified as possible solutions.

To close the panel, our moderator, Mario Muredda, asked the panelists to suggest one tangible change that Imagine attendees could bring to life to make progress towards alleviating the burden brought on by CRFT. The following suggestions from panelists drove much of the conversation as the day progressed and are now informing the prioritization of program development post-Imagine:

- Financial planning for families in treatment
- Increased awareness of CRFT earlier in the treatment journey
- Mortgage forbearance policy
- Insurance and resource navigation in the hospital or treatment setting.

## **Session 2**

### ***Big Data: The Full Scope of Financial Toxicity***

***Speaker: Peter Merrigan, CEO, Taurus Investment Holdings***

#### **Objectives:**

Oncology researchers have embraced cancer-related financial toxicity over the past decade, publishing more research on its impact on patients and caregivers. The primary goal of this session was to share the existing data on CRFT to demonstrate the magnitude and severity of this problem, highlighting the clinical impact that financial hardship can take on a patient's chance of survival. The secondary goal was to demonstrate the gaps that exist in research to support Family Reach's hypothesis that proactive financial intervention can improve a patient's chance of survival and will reduce overall spending for a health system and the broader US economy.

#### **Summary & Conclusions:**

Peter Merrigan outlined the research and data currently available surrounding CRFT. He discussed what CRFT means for a patient, the occurrence of CRFT in pediatric and adult cancer populations and its clinical impact. Key data points included:

- Cancer patients are 2.65X more likely to go bankrupt than people without cancer
- 1 in 3 families are unable to meet their basic needs because of a pediatric cancer diagnosis
- Up to 73% of adult cancer survivors experience CRFT
- Over 1/3 of adult cancer patients report medical or chemotherapy nonadherence as a result of financial hardship
- Children from high-poverty areas relapse sooner than children living in low-poverty areas

- Adult cancer patients who file for bankruptcy have a 79% greater risk of early mortality than those who do not file bankruptcy

The session concluded with a discussion of possible solutions to better quantify the problem through more data collection and analysis. Topics addressed included:

- Mortgage forbearance/reverse mortgage
- Loan assistance programs
- Credit stabilization
- Employee protection programs
- Legislative action
- Collaboration with the public and private sector on data collection

### **Session 3**

#### ***Patient Resources: Today's Landscape***

##### ***Panel***

##### Objectives:

This panel united key stakeholders from the healthcare and advocacy industries to outline the current landscape of resources available to patients and caregivers.

Speakers included:

- Claudia Begino, Social Worker, Children's Hospital Orange County
- Joseph Chabot, Pediatric Resource Program Director, Dana-Farber / Boston Children's Cancer & Blood Disorders Center
- Dan Sherman, Financial Navigator, The NaVectis Group
- Ellen Miller Sonet, Chief Strategy Officer, CancerCare

##### Summary & Conclusions:

Panelists all identified the stigma surrounding financial discussions and lack of communication between healthcare professionals and patients as the leading barriers to identifying families at risk of CRFT. Many stories were shared of patients missing appointments or cutting prescriptions in half when financial health was left unaddressed.

Across the board, panelists agreed that to combat this problem hospitals must:

- Put systems in place for identifying financial distress early
- Develop a specialized, certified team dedicated to resource and financial navigation

- Realize the benefits this will bring their operation - improved efficiency, reduced costs, higher life expectancy rates

#### **Session 4**

##### ***Patient Journey: Collaborative Session (All Attendees)***

#### **Objectives:**

Attendees broke into small groups during this experiential, interactive brainstorming session, stepping into the shoes of the Watsons, a middle-class family in the throes of CRFT. Groups were provided a packet full of intimate information on the family and were instructed to spend time getting to know the Watsons - a stable, healthy, supportive unit of four. Over the course of the session, they followed the Watsons as they received the devastating news that their young daughter had cancer and navigated the many financial hurdles that arose - loss of income, extensive travel to treatment and unexpected out-of-pocket medical costs. The goals of this immersive experience were to:

1. Create first-hand awareness among attendees that this problem can affect middle- and upper-class families and remove the “it would never happen to me” misconception
2. Leverage the diverse set of stakeholders and perspectives in each breakout group to generate ideas and solutions to address the challenges that the Watsons faced at different stages in their journey

#### **Summary & Conclusions:**

Attendees brainstormed possible solutions surrounding:

- Awareness
- Housing
- Food
- Transportation
- Finance

An in-depth look at the ideas identified within this session is provided in the ***Summary of Solutions (page XX)***.

#### **Session 5**

##### ***Developing the Solution: From Idea to Impact***

##### ***Panel Discussion***



### Objectives:

The goal of this panel was to allow corporate leaders the chance to demonstrate how to move from brainstorming to action on the ideas generated during the day. Speakers included:

- Paul Krasinski, CEO, Epicenter Experience
- Jon Dauphiné, Executive Director, Foundation for Financial Planning
- Eric Morse, Executive Vice President, Needham Bank
- Tyler George, General Manager, Lyf

### Summary & Conclusions:

Industry leaders in technology, transportation and finance described how the public and private sector must unite to solve this large-scale social problem. Jon Dauphiné from Foundation for Financial Planning shared his vision for his partnership with Family Reach around a pro bono financial planning platform. Eric Morse from Needham Bank suggested the opportunity for community banks to engage in mortgage forbearance for patients in active cancer treatment.

The panel discussed the idea of a “People Platform” with technology serving as the hub that connects stakeholders and resources across industries to cancer advocacy groups and patients, with an ultimate goal of preventing CRFT and bankruptcy. To bring this platform to fruition we must:

- Raise awareness of CRFT
- Build a business case backed by data
- Empower communities and corporations to participate in developing solutions to this national crisis

## **Summary of Solutions**

The discussions at Imagine revolved around four main topics - awareness, food, transportation and personal finance. Below is a high-level description of the solutions generated within each category and the stakeholder they are associated with. Family Reach is developing working groups to pioneer targeted efforts and bring these solutions to fruition, starting with the housing and food industries.

### Awareness

- **Stakeholder: Researchers within healthcare and advocacy space**

- Launch of new studies, focus groups and stronger program evaluation
  - Collect more data surrounding CRFT to demonstrate the negative impact on economic and health outcomes
- **Stakeholders: Marketing and communications industries**
  - Develop a public awareness campaign
    - Utilize numerous platforms - TV, radio, social media, print, etc.
    - Host a bold, public “stunt” to gain PR attention
    - Develop an educational speaker series, podcasts featuring family stories, oncologists, etc.
  - Produce content inserts
    - Partner with utility companies, banks, etc. to develop content that can be inserted into utility bills and mortgage statements with a call to action around, “Did you know families facing cancer might not be able to pay this bill? Add \$1 to your bill this month to support a family fighting cancer.”
- **Stakeholders: Major corporations**
  - Address CRFT in corporate best practice policies
    - Put leave policies in place to create overall awareness of the possibility of CRFT
    - Leverage this as a benchmark for corporate social responsibility
- **Stakeholder: Hospitals**
  - Implement standardization
    - Work with nonprofit organizations like Family Reach and other third parties to standardize the financial assistance process
  - Empower patients and caregivers through education
    - Family hotline for finance-related questions
    - One pagers and books on what to expect
  - Staffing improvements
    - Increase number of staff dedicated to resource and financial navigation
    - Improve access to financial navigators if there is no room for staffing changes
    - Educate staff to regularly screen for CRFT
  - Mentorship programs

- Pair former cancer patients/caregivers with current patients/caregivers to alleviate the stigma of asking for financial assistance

## **Food**

- **Stakeholder: Food retailers**
  - Donation-based programs
    - Allow customers buying groceries online or at the store to make a donation or round up and create a “keep the change” account that they can donate to families in need
    - Adopt a family campaign - grocery stores/customers adopt a local family with cancer and provide food for a predetermined amount of time
  - Discount codes for patients/caregivers
    - Can be shared with resource specialists/social workers
- **Stakeholder: Meal delivery platforms**
  - Buy a meal, give a meal campaign
    - Unite with groups like Blue Apron, Grub Hub, Uber Eats, etc.
- **Stakeholder: Restaurant industry**
  - Donation-based programs
    - Adopt a family campaign - restaurants adopt a local family with cancer and provide meals for a pre-determined amount of time
    - Recruit major chains (Au Bon Pain) to “be part of treatment” and provide vouchers to their hospital locations
  - Pay it forward model
    - Panera Cares concept allowing consumers to pay what they can
- **Stakeholder: Major corporations**
  - Reward points
    - Allow customers to donate rewards to families for purchases like groceries, meals out, etc. Ex: Donate OpenTable points.
- **Stakeholder: Local communities**
  - Cancer Concierge program

- Leverage technology to create a platform where community members can see areas of need for local families, like meals and rides
- **Stakeholders: Hospitals**
  - Enable patients to bring their own food
    - Provide a fridge/microwave in patients' rooms
    - Nearby grocery lockers for online grocery delivery during extended stays
    - Provide communal kitchens
  - On-site options
    - Hospital food pantry
    - Access to healthy, discounted foods through on-site farmers' markets

### Transportation

- **Stakeholder: Ridesharing companies**
  - Donation-based programs
    - Partner with drivers to donate free rides/hours to patients/caregivers
    - Round up to donate - money goes into a bank to pay for cancer patient/caregiver rides
  - Taxi services
    - Campaign to give taxi industry a PR boost
- **Stakeholder: Communities**
  - Ride sharing
    - "Amazing Waze" - Pair drivers w/ patients along their day-to-day routes
    - Facilitate carpool coordination among patients - Super Shuttle model
  - Volunteer drivers
    - Connect veterans, college students and/or retirees with cancer patients/caregivers to drive them to and from treatment
- **Stakeholder: Oil industry**

- Donation-based programs
  - Pool funds from waived gift card activation fees to create new gift cards for cancer patients/caregivers
  - Point-of-sale campaign giving customers the opportunity to donate
  - Offer discounts for patients in active cancer treatment
- **Stakeholder: Car dealerships and rental companies**
  - Open lot concept (think Hertz/Avis funding)
    - Host a borrower lot at hospitals with free rental-type cars readily available
  - We'll pick you up/drop you off campaign (think Hertz/Avis funding)
    - Perks for company: Building a loyal post-treatment customer base
  - Donation-based programs
    - Car dealerships donate outdated/dented models to families
- **Stakeholder: Hospitals**
  - Parking assistance programs
    - Reduced fares/parking blocks for extended visits
  - Transportation
    - Include the coordination of transportation in the treatment plan, through established partnerships with ride share and other transportation vendors
- **Stakeholder: Government officials**
  - Policy change
    - Prevent termination of insurance and/or ability to repossess cars if owner is a cancer patient/caregiver

## Finance

- **Stakeholders: Community and national financial institutions**
  - Mortgage relief
    - Write the cost of forbearance into loans, whether through legislation or getting lenders to buy into the importance of this immediate relief
    - Removing default interest on mortgage forbearance

- Recruit third-party lender to provide the immediate relief to mortgages in the form of a loan (almost like a 2<sup>nd</sup> mortgage)
  - Escrow account w/ mortgage for emergency funds
  - Enact mortgage clauses typically reserved for older Americans
  - Community Reinvestment Act - What can we learn?
- Medical relief
  - Favorable loan options for families facing high deductibles
- **Stakeholders: Insurance companies**
  - Expanded plans
    - Expand HSA/FSA plans to roll over each year without expiration
    - Expand what qualifies for coverage
  - New terminology
    - CRFT “diagnosis” that enables families to qualify for certain discounts

## Conclusion

### Synthesis and next steps:

Several themes were woven among many of the solutions discussed within each focus group. Most commonly:

- Existing Tools - Many services are in place to address CRFT. We must standardize the delivery of quality financial programs and connect the many stakeholders already working on this problem to deliver effective results more quickly
- Technology - The backbone of many solutions lies in our ability to channel the power of technology to connect people, patients, healthcare systems and corporations, government and other stakeholders
- Community & Connection - People care about people and want to give, we need to show them how and make it easy

By developing solutions across public-private lines, it is possible to implement programs that will both serve families in need and fill revenue gaps caused by CRFT when patients and families fall behind on their bills, incurring massive amounts of debt, foreclosing on their homes and filing for bankruptcy.

Since the Imagine Session, Family Reach has published a white paper summarizing existing data and expert commentary on CRFT in one comprehensive resource. The white paper – *Cancer Related Financial Toxicity and its Pervasive Effects on Patients and Families: Solving a National Health and Economic Crisis Hiding in Plain Sight* -- is available to download at [familyreach.org/white-paper](http://familyreach.org/white-paper). This resource is being used by Imagine stakeholders to open doors with economists, researchers and policy makers to begin exploring future research and program opportunities.

In response to the number one need identified by patients during the Imagine Session, Family Reach launched the *Financial Planning for Cancer* program in partnership with the Foundation for Financial Planning and the Financial Planning Association in spring 2018, connecting patients with pro bono financial planners.

Finally, leveraging the ideas generated at Imagine, Family Reach will innovate and collaborate with outside stakeholders – nonprofit, corporate and government – to solve this national crisis on a broader scale. Beginning with a network of nonprofits focused on financial programs for people affected by cancer, Family Reach seeks to establish national delivery standards for financial assistance and increased awareness of CRFT.

Among corporate and government stakeholders, Family Reach will launch committees charged with bringing solutions for housing and food insecurity for cancer patients to life. Ultimately, Family Reach envisions a national Cancer Relief Network, uniting stakeholders from transportation, housing, banking, food and retail industries to participate in sustainable programs that alleviate the financial burden of cancer for millions of Americans.

For over two decades, Family Reach has stepped in to fill the needs of families facing CRFT by providing direct financial assistance to ensure families can keep food on the table, put gas in the car and pay the bills -- but this emergent solution is unsustainable. We seek to develop mutually beneficial programs to reach more patients in need and implement sustainable change. If we act on these themes and work together, we can put solutions in place. We encourage you to ask yourself - What role can I play? Who do I know? What part of the puzzle can I place?

To get involved, please visit [www.familyreach.org/imagine](http://www.familyreach.org/imagine).

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