





### What We Do

- CREATE SUPPORT GROUPS
- EDUCATE PATIENTS & FAMILIES
- FUND STUDIES TARGETING CURE
- ADVOCATE FOR CANCER PATIENTS

### Mission

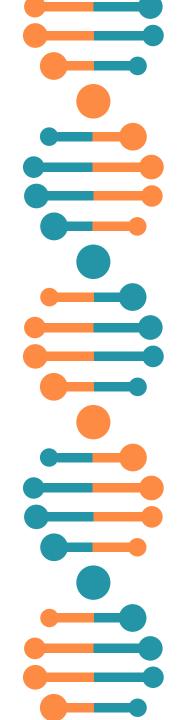
TO EMPOWER CML PATIENTS & THEIR FAMILIES TO IMPROVE THEIR QUALITY OF LIFE WHILE WORKING TOWARD A CURE

### **Vision**

A WORLD IN WHICH CML PATIENTS LIVE FULL AND ABUNDANT LIVES WITH DIGNITY AND HOPE FOR A CURE

### **Purpose**

TO SUPPORT, FUND, CREATE, AND MAINTAIN THE ESSENTIAL TOOLS FOR LIVING WITH CML







# What is CML



**CML** Impact



Need for Cure

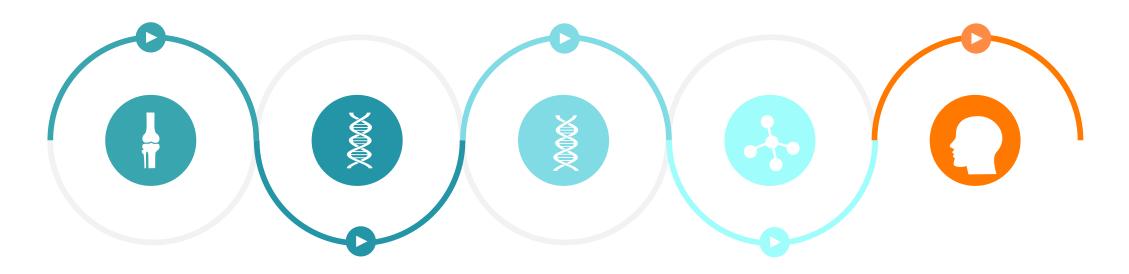


CMLBF & How You Can Help

# CML: Chronic Myeloid Leukemia



### Leukemia - Cancer of bone marrow stem cells



#### **Stem Cells**

Bone marrow cells form all blood cells

#### **Translocation**

One cell division gone awry = 2 tangled chromosomes

#### 9:22

Philadelphia
Chromosome
created
(The genetic marker
and target for CML
treatments)

#### **BCR - ABL**

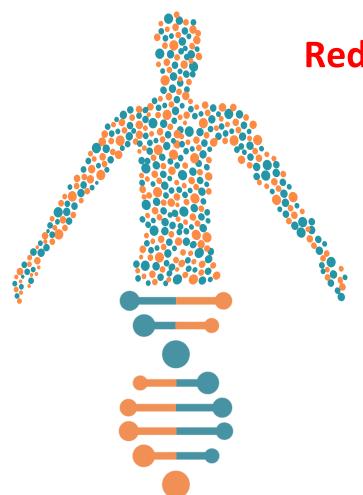
Abnormal gene produces cancer cells

#### **CML Symptoms**

Fatigue
Night sweats
Weight loss
Fever
Bone pain
Enlarged spleen

# **CML:** Rare Leukemia





# Lower visibility → Reduced research grant funding

### CML in the US

- Incidence ~2 per 100,000 CML diagnosis
- ~130,000+ in treatment 2021 US

### Lifetime rates of CML

- 1 in 526 people CML diagnosis
- CML = 15% of all leukemias

### Lifetime rates of solid tumors

- 1 in 8 women Breast cancer diagnosis
- 1 in 9 men Prostate cancer diagnosis

SEER Modeled "Long-Term Trends in SEER Age-Adjusted Incidence Rates
Calculated from SEER 9 and SEER 13 Databases: Incidence, Death rates and prevalence trends
https://www.cancer.org/cancer/chronic-myeloid-leukemia/about/statistics.html
https://www.cancer.org/cancer/breast-cancer/about/how-common-is-breast-cancer.html
https://www.cancer.org/cancer/prostate-cancer/about/key-statistics.html

# **CML:** Length of Treatment



4 - 6 Months

#### **Early stage breast**

Length of therapy for non-invasive breast cancer



#### **Acute Lymphocytic Leukemia (ALL)**

- Most aggressive childhood cancer
- > 2-3 years from induction to post treatment consolidation



#### **Chronic Myeloid Leukemia (CML)**

- > 3 month testing forever
- Studies recommend 5-8 yrs treatment prior to trial of discontinuation for those meeting criteria
- ➤ Only 50% of patients meet the criteria to attempt TKI discontinuation
- Less than 3% of patients worldwide have attempted treatment discontinuation
- > 50% of those that attempt discontinuation relapse (Return to TKI treatment)
- Over 80% of patients will remain on lifelong daily treatment

# CML Impact: CML Patients in the US Underserved





50%

#### **Access to Care**

More than 50 miles from a major cancer center

### Access to testing facility

More than 50 miles from a BCR/ABL testing facility

### **Access to CML Specialist**

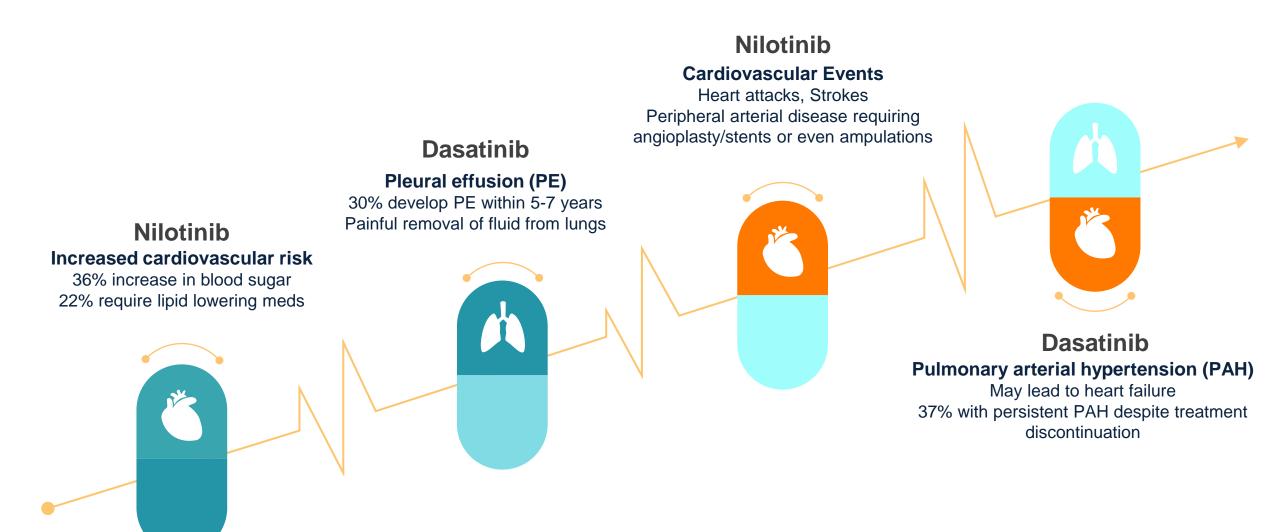
More than 50 miles from an experienced CML Hematologist-Oncologist

#### **Outcomes**

Reduced 5-year survival for patients who are uninsured or having Medicaid

# **CML Impact:** Toxic Medication Side Effects





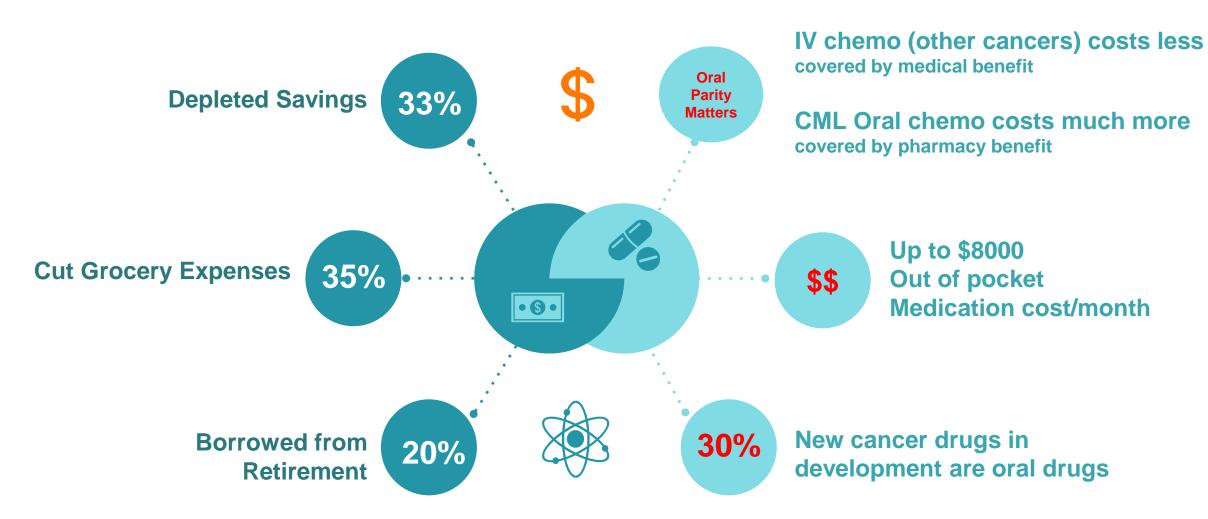
Nilotinib <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4658454/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4658454/</a> <a href="https://pubmed.ncbi.nlm.nih.gov/24658819/">https://pubmed.ncbi.nlm.nih.gov/24658819/</a>

Dasatinib <a href="https://pubmed.ncbi.nlm.nih.gov/28751413/">https://pubmed.ncbi.nlm.nih.gov/28751413/</a> <a href="https://haematologica.org/article/view/8745">https://haematologica.org/article/view/8745</a>

# **CML Impact:** Financial Hardship



# **Huge Costs - Indefinite Cancer Treatment**



# **Need for Cure:** Limited Treatment Options



# 1 Bone Marrow Transplant, 6 Oral Therapies (TKIs) 1 Infusion therapy and 3 Combo Trials

#### **Bone Marrow Transplant**

Treatment of last resort

Saved for patients with:

Accelerated phase

Blast phase

Resistant to all TKIs



#### **First Generation TKIs**

Gleevec (imatinib) Significant Daily GI side effects





#### **Second Generation TKIs**

Tasigna (nilotinib)
Sprycel (dasatinib)
Bosulif (bosutinib)
Best suited for younger healthier patients
Toxicity profile may limit use for elderly



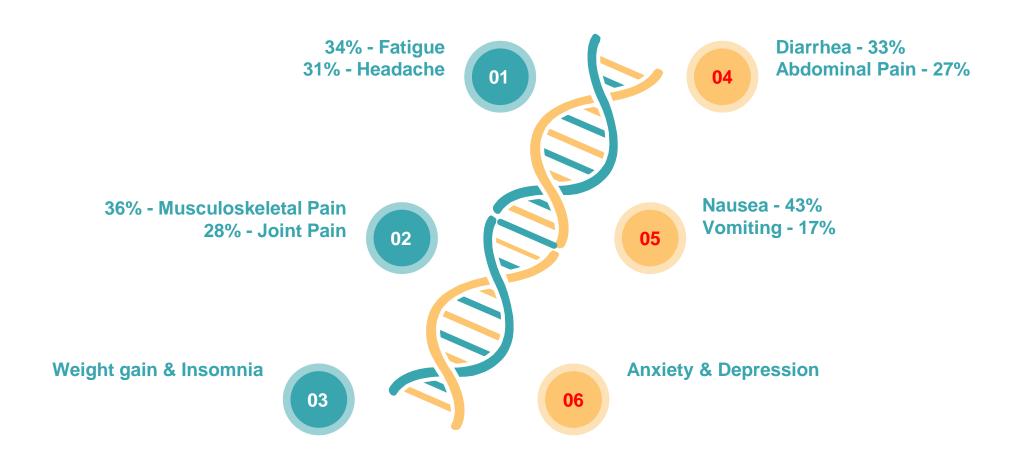
#### **Other Options**

Iclusig (ponatinib)
Asciminib (new)
Synribo (omacetaxine)
Combo Trials

# Need for Cure: Impact on Quality of Life



# Could you live with these daily symptoms for years to come?



# **CMLBF:** Why CMLBF Created



# **CML Specific: Education, Support, Research Funding Cures**

#### **Patient Support**

"I don't know anyone else with CML".

#### **Patient Support**

"There are no CML support groups in my area"

#### **CML** Awareness

"No one I talk to has ever heard of CML"

#### **CML Research - Funding Cures**

"I am only 29 and can't imagine these drug side effects for the rest of my life".

# Created by CML Patients



"To guide others like me"

#### **Patient Education - Know your PCR**

"My doctor says I am doing fine but I don't understand my lab results"

#### Patient Education - Know your TKI

"My doctor says all my new symptoms are not related to CML but they are listed on my TKI package insert"

#### Patient Education - Find a CML Specialist

"My doctor doesn't have any other CML patients and left the choice of drug options up to me."

#### Patient Education - Find a CML Specialist

"My doctor's recommendations don't seem to align with the NCCN guideline"

# **CMLBF:** Foundation Objectives

support



# **Guiding Patients & Targeting Cures**

#### **Develop Committee Support**

- **Board of Trustees**
- Patient & Medical

#### **Support CML Research**

**Identify & fund studies** targeting cures

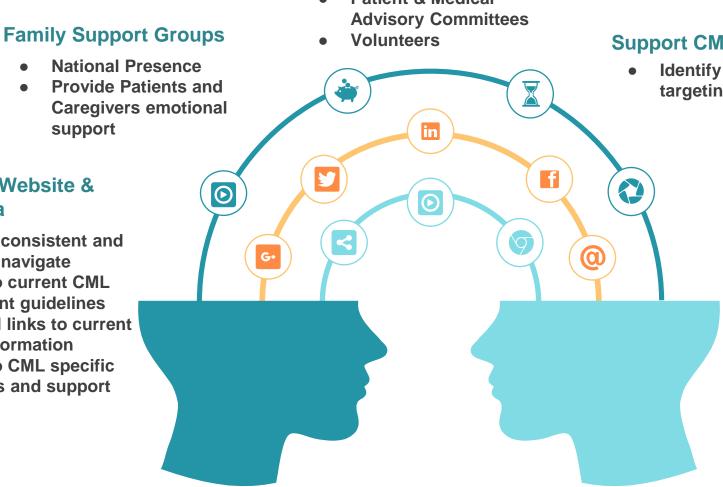
#### **Education - Website & Social Media**

- Timely, consistent and easy to navigate
- Links to current CML treatment guidelines
- **Curated links to current CML** information
- Links to CML specific services and support

#### **Directed Fundraising**

#### **Supporting**

- **CML Cures Research**
- **Education website &** social media
- **Family Support Groups**
- **Major Donor Directed**
- **General Blood Cancer** Research



# **CMLBF:** Foundation Use of Funds

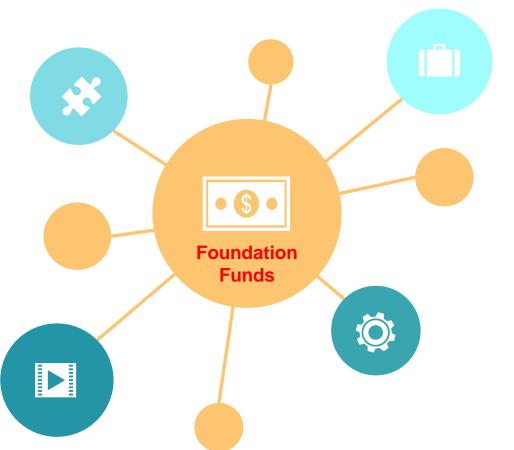


# **Guiding Patients & Targeting Cures**

#### **Donor Directed**

#### **Donors may designate funds for:**

- Funding CML Cures
- CML Patient Education
- Grow US Family Support Groups
- CML Patient Programs / Webinars
- CML Patient Voice Programs



#### **Annual Objectives**

#### **Transparency through:**

Guidestar.org - (Platinum rated)

- annual fundraising metrics
- business and mission metrics
- expenditure goals and budgets
- funding targets for cures

#### **Patients & Cures**

# Consistent funding to develop programs to:

Guide and educate patient families Real targets for funding CML cures

# costs limited to ≤ 10%

≤ 10%

**Operations & overhead** 

# **CMLBF:** Donor-Directed Funds



### **Give Your Donation a Voice**



#### **Funding CML Cures**

CML Research Study Grants
Curated by our Medical Advisory Board

#### **CML Patient Education**

Targeted CML education using web and social media Curated CML information for patient access CML specific Webinars

#### **CML Patient Support Groups**

National network of family support groups that meet monthly in each time zone

#### **CML Patient Programs**

1:1 Peer-to-peer educational guidance Bridge to other support resources

#### **Representing the Patient Voice**

Capture CML patient experience to advocate for better outcomes Patient Advisory Board driven programs and studies

# **CMLBF:** Join the Mission

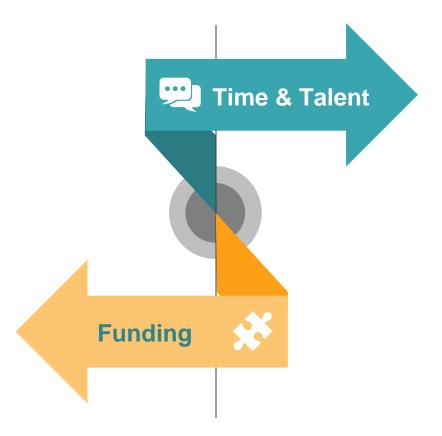


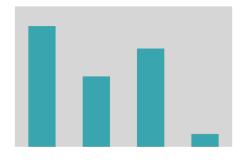
## **How Can You Help**

Join CMLBF in Funding Education, Support Services, Support Groups and Help us Focus Awareness and Fund Cures for CML

#### **Donation of Funds for:**

Funding CML Education
Funding CML Support
Funding CML Cures Research





#### **Donation of Time for:**

Advisory Committees
Advisory Boards
Administration
Fundraising
Patient Support Groups
Leadership

