

# There Goes My Hero: Color The Registry



ELEVEN YEAR  
OLD KING  
CONTINUES TO  
HOPE FOR A  
PERFECT MATCH.



"You  
could be a  
match for  
me or for  
another  
person  
who is  
fighting  
for their  
life."



Presentation created by:  
Charis Taylor



# Hero's Mission Statement

Save lives. Provide Hope. Help those impacted by blood cancer.





# Why Diversity Matters with Bone Marrow



- Bone Marrow compatibility is based in large part on ethnicity
- Geneau's donor will most likely be of minority descent (Geneau is Caribbean American)
- It is not a guarantee that her donor will be a minority but this is what the science seems to indicate
- Unfortunately there are not a lot of minorities, especially African Americans that are registered with the Bone Marrow Registry
- There is only a 11% chance of a match within the registry if you are African American



# WHAT IS A BONE MARROW TRANSPLANT?

# 1. Peripheral Blood Stem Cell donation (PBSC)

PBSC Definition: non-surgical procedure that collects blood stem cells via bloodstream. your blood is drawn through one arm and passed through a machine that filters out the blood stem cells. The remaining blood is returned to you through your other arm. To increase your blood stem cells prior to donation, you will receive daily injections of a synthetic protein called filgrastim.

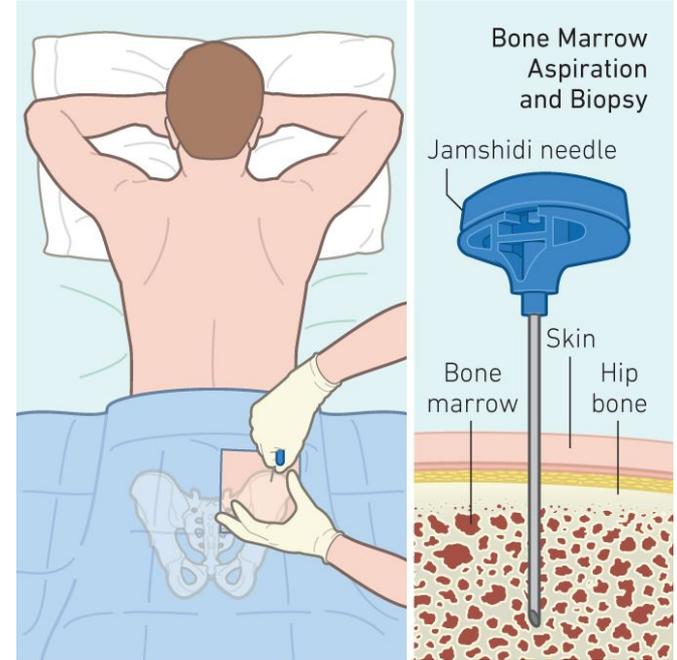
- used in about 75% of the cases
- takes about 4-8 hours
- Headaches, bone & muscle aches, fatigue (1 week recovery)



## 2. Bone Marrow Transplant

Bone Marrow Transplant Definition: procedure performed under anesthesia, so no pain is experienced during the donation. Marrow cells are collected from the back of your hip bone using a syringe. Generally takes place when the patient is a child.

- used in about 25% of cases
- Takes about 1-2 hours
- Bruising, stiff (3-6 weeks recovery)



- The donor can NOT pick which procedure they receive
- Neither hurts, just small discomfort

# Diseases Treatable by Transplants

- Leukemia
  - acute myeloid leukemia
  - acute lymphoblastic leukemia
  - chronic myelogenous leukemia
  - chronic lymphocytic leukemia
- Lymphoma
  - Hodgkins lymphoma- based in lymph nodes, glands
- Myeloma
  - starts in bone marrow, affects “plasma B cells” which are specific type of white blood cells
- ★ Other diseases that can sometimes be treated with bone marrow donation include Sickle Cell disease, aplastic anemia, and immune disorders



LEUKEMIA &  
LYMPHOMA  
SOCIETY®

# What is the Color the Registry Initiative about?

Our Color The Registry initiative seeks to diversify the bone marrow donor registry, offering hope to all patients in need of a bone marrow transplant, regardless of their ethnic or racial background.



- This project aims to close the racial gap in bone marrow transplants by increasing access to transplants for traditionally underserved communities, improving understanding of health issues in diverse communities, and increasing the quality of life for patients of color
- We want to increase the odds for patients by conducting more drives to help dispel misinformation and highlight the need for donors in the African American and Latino communities

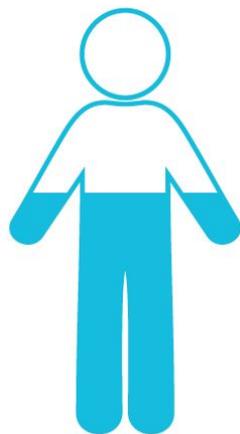
# Lack of Diversity on the Bone Marrow Registry



**Latino**

**55%**

Cannot find a matching donor



**Asian American**

**60%**

Cannot find a matching donor



**African American**

**75%**

Cannot find a matching donor



**Multi-Racial**

**75%**

Cannot find a matching donor

# The Disturbing Facts: The Shortage of diverse donors on the registry costs lives.



- Every year, **17,500 people will NEED a bone marrow or cell transplant to cure their blood cancer or disorder**
- This includes diseases like Sickle Cell and Multiple Myeloma, which **disproportionately affect the African American community**
- Only 30% of patients are able to find a matching donor in their family. The rest rely on the 33 million registered donors
- Because the registry lacks diversity, patients of **African, Latin, & Asian descent have a harder time finding a match**

# The Disturbing Facts:

Ancestry is the KEY to a perfect match between donor & recipient.



- The factors tested to make sure the donor and recipient are a match and the transplant can work are called Human Leukocyte Antigens (HLA)
- **The best chance of finding a perfect HLA match is with someone of the same ethnicity**
- Multi-racial/ethnically diverse individuals often have rare combinations of antigens in their HLA profiles, making it **even harder to find a match**
- It is **urgent** that more multiracial individuals join the registry

# The Disturbing Facts:

Myths about donation prevent people from registering.



- Many potential registrants are concerned with how their biological data will be used; who they may be asked to donate to; and whether the procedure hurts
- **All donor health information and data is kept confidential in accordance to HIPAA laws**
- **HIPAA Law:** requires physicians to protect patients' electronically stored, protected health information (known as “ePHI”) by using appropriate administrative, physical and technical safeguards to ensure the confidentiality, integrity and security of this information
- The two methods of donating are safe, outpatient procedure

# Why The Lack?

## 1. Lack of Awareness

African Americans are simply not aware of the need to join the registry. Most do not even know it exists. We need to bring more attention to this crisis. If we continue at this pace it may take several decades to build the registry to where it needs to be.

Joining the registry is so simple today that we should already have donors ready for at least 90% of all patients who need one. The need for a better, more efficient way to recruit individuals of ethnic background is apparent.

# Why The Lack?

## 2. Lack of Trust

African Americans as well as other races are difficult to convince that they are needed to join and are harder to locate and convince they need to donate once matched.

There is a deep mistrust of the Medical system among us. Because of past abuses including the infamous “Tuskegee Experiment” we have do not trust the system.

This culture of mistrust forced us to deal with health issues internally using the best resources we had (family and the church community). However, that culture which once protected us from harm's way now threatens our ability to receive proper health care and in this case, a life saving bone marrow transplant.

# How Do We Fix This?

## Nationwide Network!

We must have more communication among the existing and new organizations whose focus it is to recruit ethnic individuals to the registry.

We as a nation need to come together for a greater cause and help save lives.

# How can YOU help NOW? **GET INVOLVED!**

- ❑ **Become A Hero!**
  - ❑ Get swabbed & potentially save someone's life
- ❑ **Volunteer With Hero!**
  - ❑ Be an ambassador
  - ❑ Help assist with drives and fun fundraising events
- ❑ **Support A Patient!**
  - ❑ Donate to the cause/ Help a patient through treatment
- ❑ **Host A Bone Marrow Drive!**
  - ❑ Help diversify the registry





Any Questions? Any Concerns?

