REPORT TO THE COMMUNITY





# IT'S TIME TO GIVE PATIENTS LIKE RUSHI AN EQUAL CHANCE OF FINDING A MATCH.



When 8-year-old Rushi asked to join the baseball team with his friends last spring, his doctors told him it was too dangerous. When he asked about soccer or running, the answer was the same—
"No."

Diagnosed with beta thalassemia major before birth, Rushi has made countless trips to the hospital and needs blood transfusions every three weeks. He's at risk of heart and liver failure, and physical activity puts him at risk of rupturing his enlarged spleen.

Rushi excels in school, attends math enrichment classes, and pursues his passion for sports cars, but he really wants to play sports with his friends.

"It's getting to him," explains his mother, Nilima.
"I see him playing on the computer trying to
forget he can't do what other kids can because
of his condition."

Rushi's best hope for a cure is a blood stem cell transplant. Unfortunately, there is currently no genetic match for Rushi on the Be The Match Registry.®

Rushi's parents are from India, so he's most likely to match a donor who shares his South Asian ancestry. But of the 20 million potential donors on the Be The Match Registry, less than 300,000—or only 1.3%—identify as South Asian. Currently, South Asian patients only have a 38% chance of finding a match. Adding more South Asian members ups the odds, to help give patients like Rushi hope for a healthy future.

"Now that he's older Rushi understands why he doesn't have the energy to do things, but his anxiety on transfusion days is very high," Nilima said. "We tell him he has to be strong, but most of all, we just want him to find a donor so he can be healthy."

#### **OUR MISSION**

#### WE SAVE LIVES THROUGH CELLULAR THERAPY

At Be The Match, our dedication to saving lives inspires us to do all we can for our patients. In our 30+ years of service, that mission has never changed. But as the need for life-saving transplants continues to grow, so must we. That's why, looking forward, we embrace a new sense of urgency.

#### It's time.

To meet the needs of every patient, we must remove barriers that prevent people from finding a cure. We must grow and diversify the registry, improve donor availability, and remove financial barriers to treatment.

#### It's time.

We constantly reassess where we are, where we want to go, and determine how we will get there.

To achieve our vision, we must deliver today and plant the seeds for a better tomorrow.



Dr. Randy Mills, CEO

Thank you for sharing in our mission, and embracing our urgency. The time for saving lives is now.

#### C. Randal Mills, Ph.D.

Chief Executive Officer, National Marrow Donor Program® (NMDP)/Be The Match® Executive Director, Center for International Blood and Marrow Transplant Research® (CIBMTR)

#### **Joy King**

Executive Director, Be The Match Foundation®
Chief Advancement Officer, National Marrow Donor Program® (NMDP)/Be The Match®

## Equal Outcomes for All

## **OUR VISION** DEMOCRATIZE CELL THERAPY EQUAL OUTCOMES FOR ALL

#### Our commitment

Regardless of background, socioeconomic status, age, ethnic ancestry, or location, we are committed to creating equal outcomes for all. We have an obligation to serve all patients in need. We will strive to remove the element of luck from the equation. Receiving life-saving cell therapy will not be predicated on how much money a patient has, whom they know or their ethnic background. Everyone will have access to a great cell therapy.

#### Strategic themes

Our strategic themes are the guiding principles which we employ to achieve our vision.



Our business is saving lives. To improve, we must drive innovation.

We need new solutions to ensure there are successful cell therapies with great outcomes for every patient who needs us.

Therefore, we will boldly search for ways to improve patient and donor experiences.



By generating higher demand for Be The Match products and services, we will grow our infrastructure and provide a superior offering for the patients we were created to serve.

To achieve critical mass, we will increase the usage of our products and services by expanding into underserved or emerging cell therapy markets.



In order to grow, we will need to improve clarity, speed and service.

We are going to remove complexity, duplication and points of failure.



BE THERE responsively serving

Experiencing first-hand what our customers face will enable a faster, more accurate response to their needs and provide inspiration for continuous innovation.

We will be there with our customers—patients, providers and donors—to directly share in the experience.

#### Expected results

ordered.







25% increase

in event-free survival rate for our core patients.



50% increase

in the number of people in the U.S. who receive Be The Match-facilitated cell therapy.



Double

treatment volumes in underserved populations with no discernible differences in outcomes.

#### TO HELP PATIENTS LIKE ROMAN FIND THEIR LIFE-SAVING MATCH

Roman is a delightful 3-year-old boy who was diagnosed with Shwachman-Diamond syndrome when he was only 6 months old. This rare disease causes him to produce zero white blood cells, which are necessary for fighting infection. Something as minor as a common cold could kill him.

Roman has been in and out of the hospital his whole life. His doctors have done everything in their power to manage his symptoms, but a blood stem cell transplant from a matched donor is the only hope for a cure. Roman's blood work started to change recently and the family fears that a transplant will be needed soon.

"We were told that there was a less than 1% chance of Roman finding his match because of his mixed, Chinese/Italian heritage," said Roman's mom, Nicole. "But you know what? "I'm his mom, I WILL find his match, no matter what. I carry swabs in my purse. I'll register anyone I meet.



## TO RISE UP, TO SHATTER RECORDS AND CREATE A NEW REALITY

#### Lemons for Leukemia Challenge sets new world record

When Chris Betancourt, 20, was diagnosed with chronic myeloid leukemia, he was given one year to live. When his best friend, Dillon Hill, 19, got the news, he took time off from college to help.

"I couldn't sit in a lecture hall while he was potentially dying. Chris was afraid of not being able to experience things in life he wanted to do, so we made a bucket list and documented every single moment of it," Dillon said.

One of the items was to set a world record for blood stem cell donor registrations in 24 hours. The pair created the Lemons for Leukemia Challenge, which involved posting a video of yourself biting down on a raw lemon, challenging others to do the same, and encouraging people to join the Be The Match Registry®.

The campaign went viral, landing a spot on Good Morning America, where anchor Robin Roberts, who is a blood stem cell transplant recipient herself, accepted the challenge.





Thanks to the support from people across the nation, Chris and Dillon achieved their goal, setting a new world record by recruiting nearly

4,000 people in 24 hours

#### TO MAKE **TRANSPLANT** FINANCIALLY ACCESSIBLE TO **EVERY PATIENT**

Instead of being surrounded by family, balloons and party favors to celebrate her 1st birthday, Dezi was surrounded by doctors and medical equipment. When Dezi was diagnosed with acute myeloid leukemia, her parents went from thinking about birthday gifts to figuring out how they would get her the life-saving blood stem cell transplant she needed—especially since their insurance wouldn't cover the cost to help them find her match.

Thankfully, a Search Assistance Fund grant from the Be The Match Foundation® made it possible to find her a cord blood unit without delay.

Additionally, a Transplant Support Assistance grant of \$2,000 helped offset the costs associated with having to move close to the transplant center, as well as lost income due to Dezi's mom Dessica having to quit her job to care for her daughter.



#### PATIENT ASSISTANCE GRANTS HELP FAMILIES FOCUS ON HEALING.

**Average Transplant Grant Recipients** 

relocated for treatment.

decrease in income.

Expenses exceeded income by \$1.000/mo

I am such a grateful mother! Without your generosity we would still be battling AML or something even worse."

## TO ADVOCATE ON BEHALF OF PATIENTS

Lisa Maxson lives with her husband and three children in the small, close-knit community of Troy, Ohio, just outside of Columbus. When she was diagnosed with acute myeloid leukemia, there was no donor match for her in her family. Fortunately, she was able to receive a life-saving cord blood transplant.

Out of gratitude and a desire to pay it forward to help other patients, Lisa and her dad, Tom, have been instrumental in hosting the Buckeye Walk+Run To Go event, raising more than \$40,000 for Be The Match in the last few years.

In addition to their own efforts, Lisa and Tom participated in Legislative Advocacy training to share their experience with lawmakers to help improve all patients' access to treatment.

"If it wasn't for Be the Match, I wouldn't be here today to experience life with my husband and three kids.

I believe it is important to continue advocating to ensure others have the same opportunities I have had because of cellular therapy."

- Lisa Maxson, cord blood transplant recipient



#### **RELATED DONOR SERVICES**

Related Donor Services allows transplant centers to focus on their patient care, while we focus on managing:

- Sample collection for HLA typing of family members
- Related donor workup and blood stem cell collection
- Donor and patient benefits, resources and support

Related Donor Services takes a lot of the stress off donors. They are able to provide the lifesaving transplant for their loved one with less travel and less hassle.

Mindy Allen, R.N., B.S.N., C.H.T.C., B.M.T.C.M Blood and Marrow Transplant Coordinator The University of Kansas Cancer Center

#### BE THE MATCH BIOTHERAPIES®

Be The Match BioTherapies partners with companies advancing new cell and gene therapies. In 2018, as an extension of our life-saving mission, we:

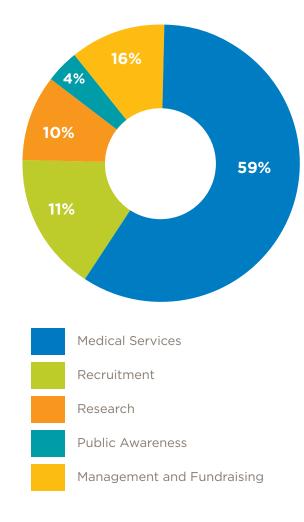
- Provided services to 14 cell and gene therapy companies to help develop 12 new therapies
- Launched industry-wide efforts to improve delivery of cell and gene therapies to patients
- Expanded our global Network, including a partnership with Cellex Cell Professionals in Germany

There's so much potential to provide new innovative therapies for diseases in which there were previously little to no treatment options available. Working to advance life-saving science and bring positive outcomes to patients is what Be The Match BioTherapies is all about.

Jaime Margolis, P.h.D.
Director, Cell & Gene Therapy Operations



## HOW WE SPEND EACH DOLLAR



#### **FINANCIALS**

NATIONAL MARROW DONOR PROGRAM AND SUBSIDIARIES CONSOLIDATED STATEMENT OF FINANCIAL POSITION AS OF SEPTEMBER 30, 2018 (IN THOUSANDS)

ASSETS	
Current and other assets	\$149,817
Long-term investments and bond reserves	114,091
Property and equipment	107,162
TOTAL	\$365,070

LIABILIT	TIES AND NET ASSETS	
Current	and long-term liabilities	\$135,444
Net ass	ets	229,626
TOTAL		\$365,070

#### CONSOLIDATED STATEMENT OF ACTIVITIES FOR THE YEAR ENDED SEPTEMBER 30, 2018 (IN THOUSANDS)

REVENUES AND GAINS	
Search and procurement fees	\$348,146
Federal contracts, cooperative agreements and contributions	69,101
Investment and other income	343
TOTAL	\$417,590

	EXP	ENS	SES
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Program services	\$345,463
Management and general	67,137
Fundraising	1,747
TOTAL	\$414,347
TOTAL  Non-operating income	<b>\$414,347</b> 6,398

To read our consolidated audited financial statements with supplemental schedules, visit: **BeTheMatch.org/audit** 

#### OUR GLOBAL NETWORK OF CARE

From the moment doctors search our registry for a blood stem cell donor or cord blood unit, to the safe delivery of the life-saving cells to patients' bedsides for transplant, and for years after, we are there every step of the way. Our global Network counts on our technology, expertise and unparalleled logistical support to make blood stem cell transplants possible.

#### **BE THE MATCH NETWORK**

25	Domestic Donor Centers
70	Collection Centers
84	Apheresis Centers
152	Transplant Centers
8	Testing Labs
28	Recruitment Groups
54	International Donor Centers and Cooperative Registries
10	M

Member Cord Blood Banks

#### **2018 AT A GLANCE**

**REGISTRY** 

6,200

TRANSPLANTS IN FY2018

By Cell Source **68%** 

PERIPHERAL BONE
BLOOD STEM CELL MARROW

**21%** BONE

CORD BLOOD

11%

Likelihood of having a matched, available donor on the Be The Match Registry by Patient Ethnic Background

African American or Black 23%

Asian or Pacific Islander 41%

Hispanic or Latino 46%

American Indian and Alaska Native 57%

White **77%** 

RESEARCH

NUMBER OF PUBLICATIONS IN 2018

TRANSPLANT CENTERS,
HOSPITALS, AND UNIVERSITIES
PARTICIPATING IN RESEARCH



#### PATIENT ASSISTANCE



2,200

PATIENTS RECEIVED FINANCIAL ASSISTANCE IN 2018

We provide one-on-one support, information and resources for transplant patients, caregivers and families, including patient assistance grants to help ease the financial burden of uninsured costs associated with treatment.

MISSION SUPPORT

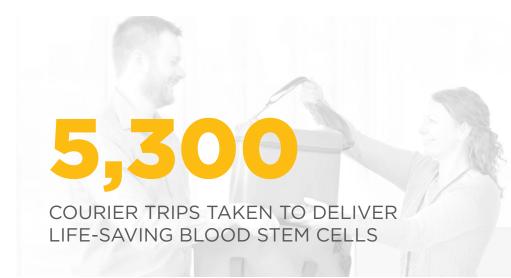
\$9.8 MILLION
IN FINANCIAL CONTRIBUTIONS

24,000

CONTRIBUTIORS

\$3.6 MILLION

VALUE OF VOLUNTEER HOURS



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Our mission: raising funds to give patients hope for a cure

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Be The Match Foundation has invested nearly \$9 million to support the career development of 37 emerging leaders in the field of transplant research focused on the treatment and prevention of postcellular-therapy complications. The Amy Scholars have leveraged this funding to win more than \$110 million in additional funding to help more patients live longer, healthier lives. Today, the Amy Program is one of the largest and most coveted fellowships in the field of transplantation.



Craig Byersdorfer, M.D., Ph.D. University of Pittsburgh

Manipulation of T cell metabolism to treat and prevent acute graft-versus-host disease



#### Joshua Hill. M.D. Fred Hutchinson Cancer Research Center

Genome-wide host expression to diagnose infectious and non-infectious causes of lower respiratory tract disease after hematopoietic cell transplantation



Rayne Rouce, M.D. Baylor College of Medicine CD19 Multivirus-Specific T cells as treatment and

prevention of relapse and viral infections posthematopoietic stem cell transplant



Enrico Velardi. Ph.D. Memorial Sloan Kettering Cancer Center

Strategies to enhance post-transplant immune reconstitution

The generosity of our mission supporters makes these awards possible. Together, we are advancing blood stem cell transplant science to help thousands of patients live longer, healthier lives.

#### THANK YOU INDIVIDUAL CONTRIBUTORS.

Our mission would not be possible without our caring community of financial supporters. We are deeply grateful to these individuals who have generously supported our life-saving work through philanthropy. Listings recognize cash contributions, pledges and pledge gifts.

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#### **MOORE FAMILY GIVES** \$1 MILLION TO SUPPORT TRANSPLANT RESEARCH



**Longtime supporters Tom and** Sally Moore recently made a \$1 million gift to the Be The Match Foundation®, to advance transplant research through the **Amy Strelzer Manasevit Research** Program. Their gift was inspired by their granddaughter Lauren's transplant experience, and their desire to help other patients and families.

Today, Sally describes nine-yearold Lauren as "vivacious, fast, furious, full of fun, with a great sense of humor." She's come a long way since 2011 when she was first diagnosed with rare, T-cell acute lymphoblastic leukemia. She was hospitalized for multiple rounds of chemotherapy when she was only two years old. Realizing Lauren's only chance of a cure would be a blood stem cell transplant from

a genetically matched donor, Lauren's doctors began a search of the Be The Match Registry®

Lauren's mother, Nicole was nine months pregnant at the time with Lauren's baby brother, Tommy. While a transplant of blood stem cells collected from the umbilical cord blood might have provided a cure for Lauren, they were not a close enough genetic match. That's not unusual, as 70 percent of patients who need a transplant do not find a fully matched donor in their family.

Fortunately, a donor was found—a young woman named Kristen—who had joined the registry when she was in high school, and followed through on her promise a few years later to provide Lauren's cure

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#### THANK YOU LIFETIME AND LEGACY CONTRIBUTORS

A financial investment of \$250,000 or more is transformative for our work. These generous supporters have demonstrated a tremendous commitment to our life-saving mission through their lifetime giving of \$250,000 or more.

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#### ADMIRAL ELMO R. ZUMWALT, JR. AND MOUZA COUTELAIS-DU-ROCHE ZUMWALT **LEGACY SOCIETY**

Our legacy society recognizes those supporters who have designated Be The Match as a beneficiary of their will, trust, retirement plan assets or insurance policy.

Lynn Abrahamsen

J. Gregory Cesario Mike Charewicz

> Mouza Coutelais-du-Roche<sup>†</sup> and Admiral Elmo R. Zumwalt, Jr.†

Steven Daniels

Bonnie and Gary Goldberg

#### PAYING IT FORWARD TO CREATE A LASTING **LEGACY**



Paying it forward is a value that Gary Goldberg holds dear to his heart. Twenty years ago, Gary joined the Be The Match Registry® in hopes of matching a little boy in his community who was searching for a donor. Unfortunately that boy did not find a match, but a year later, Gary was identified as a perfect match for a different 10-year-old boy. Gary went on to donate his marrow, saving the boy's life. "There is nothing like it. I know how important being a match is and what little effort it takes to save someone's life," said Garv.

Gary continues to be a passionate supporter of Be The Match. "Whether I'm attending an event, raising funds, or making introductions, I want to connect people to Be The Match."

Gary and his family recently made the decision to support Be The Match with a planned gift. "We were doing some financial planning, looking at charities, and Be The Match was at the top of the list. Planned giving is an easy way to continue to pay it forward and create a living legacy."

† DECEASED † DECEASED

#### THANK YOU CORPORATIONS, FOUNDATIONS AND ORGANIZATIONS

Our corporate, foundation and organizational partners provide critical financial support to accelerate our mission and are committed to saving more lives through cellular therapy eash contributions, pledges and pledge gifts.

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#### **LabCorp PARTNERS** WITH BE THE MATCH



Be The Match® and LabCorp have enhanced their 25-year partnership by launching a joint donor recruitment campaign at LabCorp patient service centers.

This initiative is the beginning of a multi-year joint program to increase registry enrollment, with a particular goal of adding more members, aged 18-44, from diverse ethnic backgrounds.

"This program to increase awareness of the Be The Match Registry is a natural fit with LabCorp's mission to improve health and improve lives," said David P. King, chairman and chief executive officer of LabCorp. "Supporting awareness and donor registration through our patient service center network will help increase registry participation, particularly among underrepresented groups, and will improve the quantity and quality of donor matches."

- David P. King, chairman and chief executive officer of LabCorp

#### THANK YOU VOLUNTEERS

Last year, our incredible network of volunteers contributed more than 148,000 hours of their time. This investment of talent saved Be The Match more than \$3.6 million, all to better serve our patients and their families. The following amazing volunteers **gave 100 hours or more of service this past year.** 

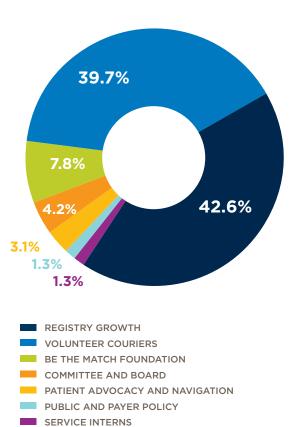
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### THANK YOU TOP ONLINE PEER-TO-PEER FUNDRAISERS

Those who fundraise on behalf of Be The Match make a tremendous impact. By engaging their personal networks, these champions raised \$5,000 or more, either personally or through a team, to directly support our mission.

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Team Ben - Todd Teach

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THROUGH TEAM
BE THE MATCH

**HONORING HADI** 



Hadi was 7 years old when his twin brother, Zakaria, threw a book at him, resulting in a black eye. His parents didn't think much of it until they noticed bruises on Hadi's back. A trip to the pediatrician led to a diagnosis of aplastic anemia. The only cure would be a blood stem cell transplant. Hadi had many matches on the Be The Match Registry®, but sadly, two transplants from the same donor were both unsuccessful and Hadi lost his battle.

"I want to do my part to help other kids find their matches," said Hadi's mom, Saira. "It's what Hadi would want."

In 2018, Hadi's family joined Team Be The Match, raising more than \$58,000 to add new donors to the registry. Their goal for 2019 is \$100,000 to help carry the dream forward.

Team Be The Match is an opportunity to rally friends and family to create brighter futures for patients and their families. It's easy, it's fun, and so, so rewarding."

- Saira, Hadi's mom

## THANK YOU BOARD OF AMBASSADORS

Members of the Be The Match Board of Ambassadors (BoA) play a crucial role in our mission, serving as representatives of Be The Match within their community. These volunteers are dedicated to identifying, engaging and building relationships with individuals and corporations in support of Be The Match Distinguished Events to advance our life-saving mission.

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#### SERVING IN HONOR OF HIS SISTER'S MEMORY



As a volunteer member of Be The Match's Board of Ambassadors, the work of Be The Match is very personal to me. Thirteen years ago, I was diagnosed with acute myeloid leukemia. A blood stem cell transplant was my only hope for survival. Fortunately, my older sister, Riley, was a near perfect match and the transplant was successful.

Tragically, we lost Riley in an automobile accident just one year after she gave me her life-saving cells. In honor of Riley's memory, I am deeply grateful to be here today to volunteer with Be The Match, making transplants possible for the 70 percent of patients who do not have a donor match in their family.



Riley did something uniquely special and life-saving for me and I am committed to use the gift she gave me to help Be The Match save even more lives."

- Roger Paschke, transplant recipient; board member. Be The Match Foundation

#### THANK YOU MONTHLY SUPPORTERS

Our monthly contributors provide reliable, consistent financial support to Be The Match, helping deliver life-saving blood stem cell transplants all year long. This dedicated group of supporters is committed to giving \$25+ each month to save lives.

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