

Iranian Donors Save Lives: Collaborating with Community Advocates to Address Racial Disparity in Access to Unrelated Donors for Allogeneic Transplantation

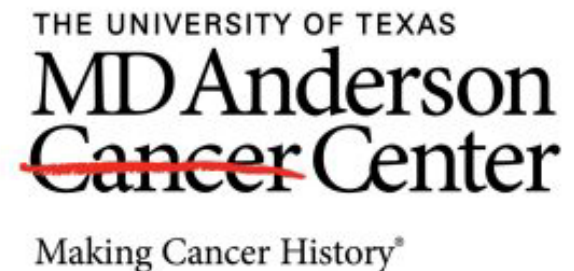
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Background

- Engaging with underserved communities: critical to address disparities.
- However: little work has explored how to collaborate with community advocates.
- Iranian peoples: underserved population & largely untapped donor pool (esp. diaspora in US, Canada, Europe).



Farnaz Farahbakhsh
Lead, Iranian Donors Save Lives

Project aims:

1. Develop & evaluate campaign to engage Iranian peoples to stem cell donation, in partnership with Iranian advocates.
2. Examine barriers & facilitators to community engagement.

Iranian Donors Save Lives: Multimedia

Starring 33 Iranian-advocates

Infographics in English & Farsi emphasizing racial disparity

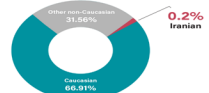
Stories & appeals from Iranians impacted

Video testimonials & TikToks¹ featuring Iranian advocates

آیا می دانید که: بیماران ایرانی نسبت به سایر مردم جهان دسترسی کمتری به اهداکنندگان سلول های بنیادی دارند؟

بیماران مبتلا به سرطان خون ممکن است برای درمان، به پیوند سلول های بنیادی نیاز داشته باشند در صورتی که اکثر آن ها اهداکننده ی سازگاری در خانواده خود پیدا نمی کنند. احتمال پیدا کردن اهداکننده سازگار برای بیماران ایرانی از خود ایرانیان خیلی بیشتر از نژاد های دیگر هستند؛ اما تعداد ایرانیان در لیست اهداکنندگان سلول های بنیادی در کانادا و سایر نقاط جهان خیلی کم است.

اما کمتر از ۲٪ درصد از اهداکنندگان ثبت شده در جهان، ایرانی هستند.



ایرانیان یک درصد از جمعیت جهان را تشکیل می دهند.

۱٪

شانس یک بیمار ایرانی در پیدا کردن یک اهداکننده سازگار خارج از خانواده خود چقدر است؟



به افراد ایرانی (در محدوده سنی 17 تا 35 سال)، برای ثبت نام اهدای سلول های بنیادی به شدت نیاز است.

برای کسب اطلاعات بیشتر در مورد نحوه عضویت در ثبت نام اهدای سلول های بنیادی به stemcellclub.ca/iranian مراجعه کنید. شرایط ثبت نام برای اهدای سلول های بنیادی در کشور خود را بررسی کنید. Canada - Canadian Blood Services, UK - Be the Match, Iran - ISCDP Iranian Stem Cell Donor Program, UK - the Anthony Nolan Registry.

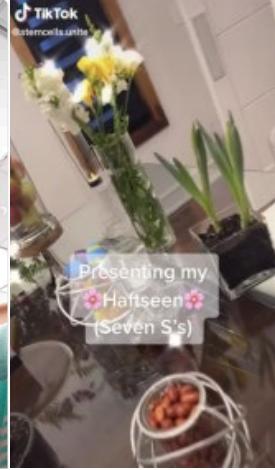
در صورت سازگاری با یک بیمار نیازمند، چگونه باید سلول های بنیادی اهدا کنیم؟

در 90٪ موارد اهدای سلول های بنیادی توسط یک روش ساده شبیه به خون دادن صورت می گیرد. در کمتر از 10٪ موارد سلول های بنیادی از مغز استخوان فرد اهداکننده جمع آوری می شود.

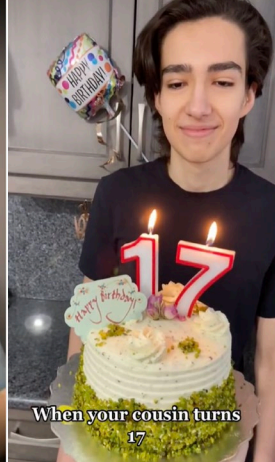
1. HEMZA, C2019. HEMZA Global Prevalence Report 2019. <https://hemza.oncopeace.com/2021/05/01/2019-Summary-Global.pdf>.
2. Gargani, L. et al. 2014. "100+ ethnic backgrounds for hematopoietic stem cell grafts in the US registry." *Annals of Hematology*, Journal of Medicine, 37(14), 339-346.



since it was extremely difficult to find a match for patients who were of
Ali, transplant candidate



Jakob, stem cell donor



Video statements from Iranian physicians



¹Park & Fingrut, BMT 2024

Selected Stem Cell Donation TikToks

All starring/ directed by Iranian advocates. <https://www.tiktok.com/@stemcells.unite>

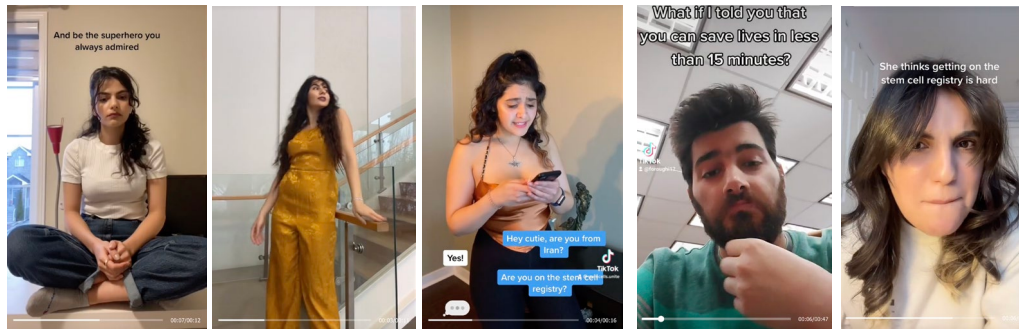
Educational topics

Disparity



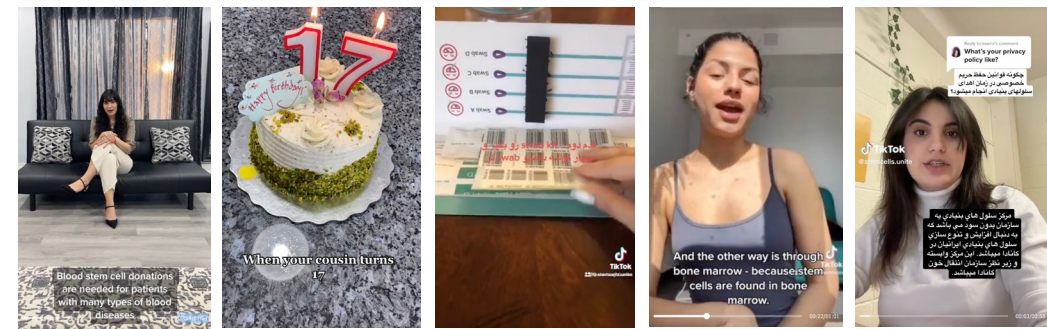
Diverse donors needed

Attitudinal guidance



Cool Fun Attractive
Social value

Donation information



Diseases treated Eligibility How to register Donation process Safety & side effects

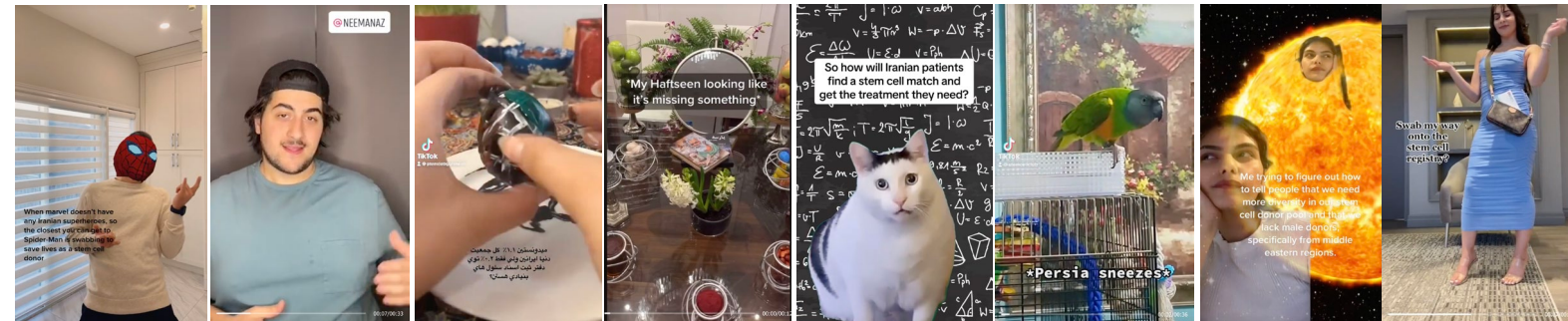
Engagement strategies

Video structure



Parallel content Plot twist

Themes

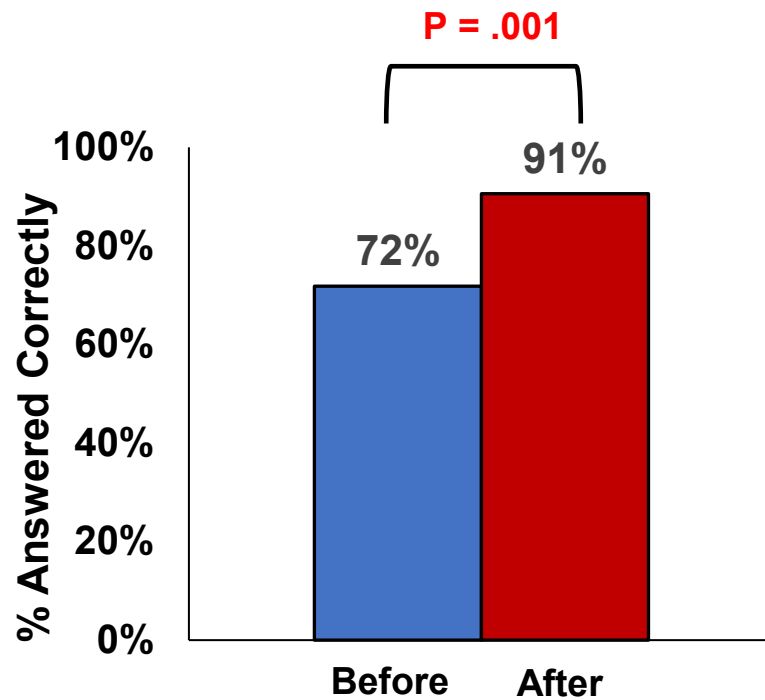


Duet Collab Pop culture Holidays Animals Gen-Z trends

Multimedia impact on donation knowledge & attitudes of young-adult Iranian-Canadians

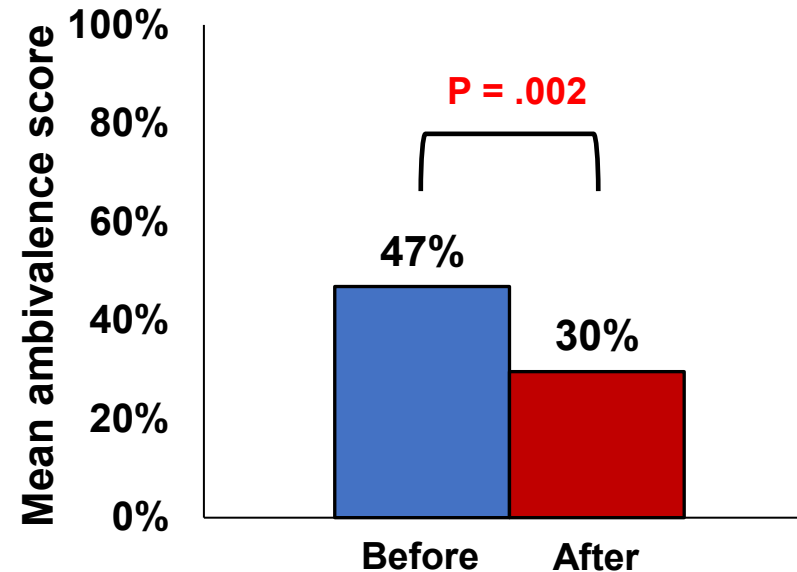
(n = 39, all 17-35 yrs, 49% male)

Donation knowledge*



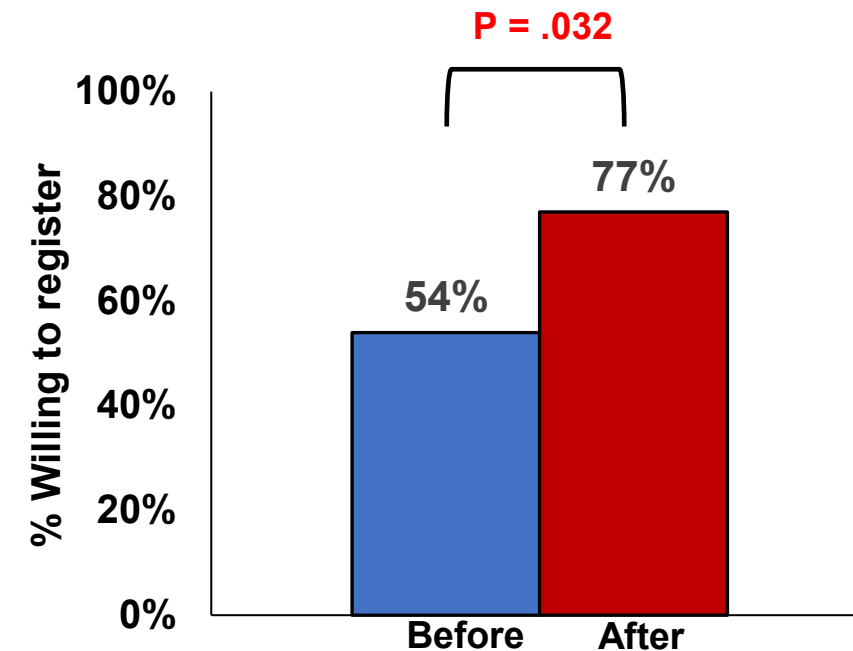
*Need for diverse donors; eligibility criteria; collection method

Ambivalence to donation**



** Based on 7-question Simmons Ambivalence Scale

Willingness to register



Viewing multimedia improved Iranian-Canadian donation knowledge & attitudes. We conducted focus groups exploring barriers/ facilitators to engagement.

Barrier: lack of knowledge about racial disparity

[Re: infographics]

“You don't realize the number of [Iranian] people who are donating stem cells - how small it is - until you actually see it.”

(Group 6, Participant 11)

Barrier: Stigma around health

“There's also a lot of stigma around health in general in our community where people are very hesitant sometimes to talk about it.” (G25P37)

[Re: testimonials from Iranian advocates]

”It definitely did impact my willingness to become a donor. The Persian community feels like family almost...

If I could help someone in that situation, I would love to.” (G2P4)

Barrier: Mistrust of healthcare

“Our culture is very mixed. We have all these different mindsets and opinions. There are people who would say things like, oh, they're going to steal my blood; they're going to do bad stuff on it.” (G6P10)

[Re: Iranian influencer testimonial]

“There's a sense of trust when you see somebody you already know advocating for this.” (G1P1)

[Re: Iranian physician statement]

“They help you make a decision if you want to sign up, because they're a doctor and also because they're from the Iranian community.” (G27P39)

Facilitator: Stories from community members personally impacted



Ali, transplant candidate

[Re: Iranian patient testimonial]

“It's hugely impacted my decision regarding stem cell donation because, fortunately, he was lucky his family was a great match for him. But there are many other people whose families are not able to do that.” (G7P13)

Facilitator: Cultural references and themes



“[Nowruz is] a time where everyone comes together, and donating to those in need is included in our celebrations. Could make a good campaign out of that!” (G9P16)

“I personally love the [Nowruz] haft-seen one – that was well done. It was really funny.” (G15P24)

“My favourite [TikTok] was probably the Marvel one. That one was pretty funny, because he's right – Iranians are not represented in the Marvel Universe. And there's other ways to save a life than, you know, being a superhero.” (G6P11)



Facilitator: Use of the languages spoken

[Re: campaign materials translated into languages spoken]

“Honestly, as a person who knows both English and Farsi, it's obviously good. I know there's a lot of Iranians who don't know English - this would help them understand everything better.” (G10P17)

Facilitator: Communication tailored to the community

[Re: campaign name “Iranian Donors Save Lives”]

~~West Asians Save Lives~~

*“If you specifically say Iranians, I would be like, ‘Oh this is, this is me’.
But if you say West Asians, I’d just pass through.” (G1P1)*

~~Persian Donors Save Lives~~

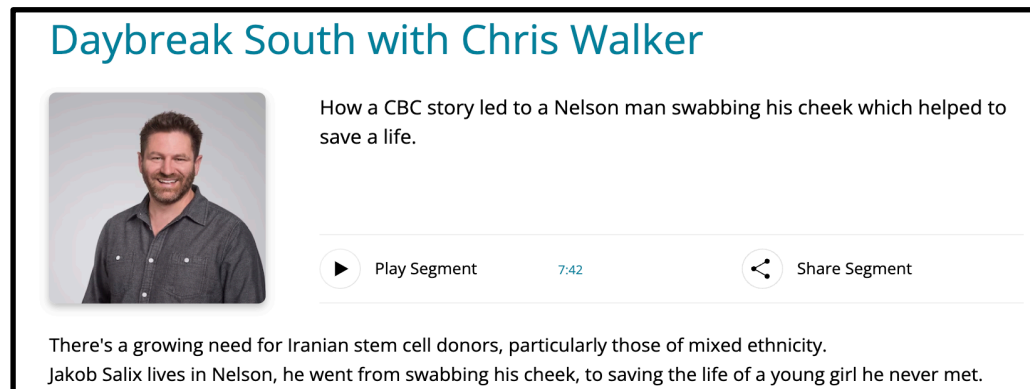
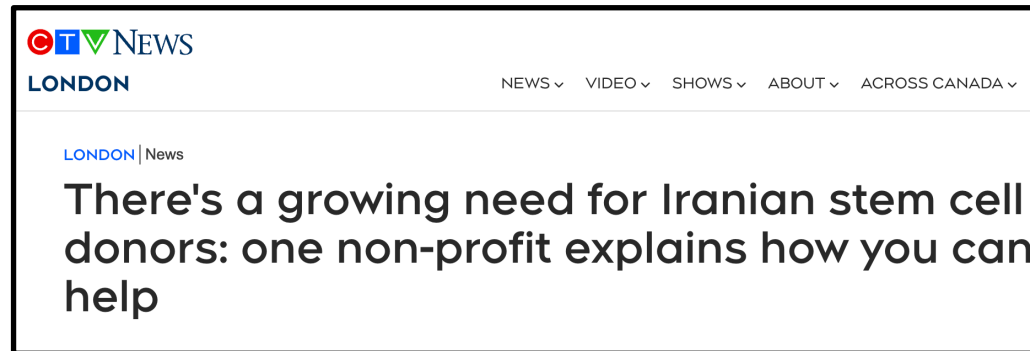
*“Not everyone [of Iranian origins] identifies as Persian.
[But] Iranian definitely captures them all. Iranian is the more neutral term.” (G3P6)*

~~Middle Eastern donors Save Lives~~

*“When you say ‘Middle Eastern donors save lives’ you’re not thinking specifically
of the Iranian nationality. You think about others in the Middle East as well.
Iranian Donors Save Lives is much clearer. ” (G13P22)*

Multimedia use: Iranian Donors Save Lives

- Iranian-Canadian advocates spearheaded Nowruz recruitment campaigns in 3/2023 & 3/2024.
- Multimedia: shared on social media by Iranian partner groups & amplified by media outlets (eg CBC News, CTV News).
- Recruited **887** potential stem cell donors.

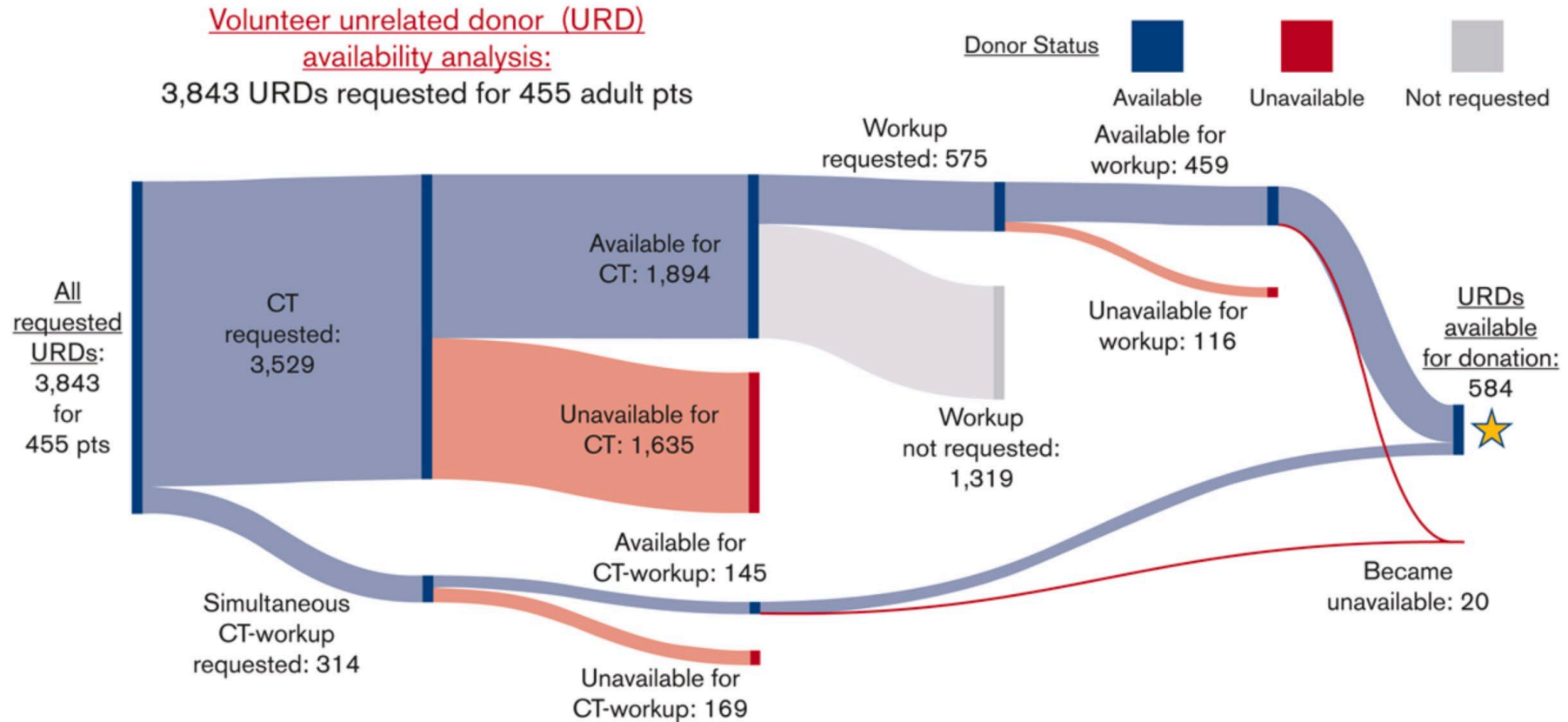


Conclusions

- **Through collaboration with Iranian advocates, we developed high-quality multimedia that overcame barriers & incorporated facilitators to community engagement.**
- **Advocates used these multimedia to spearhead campaigns engaging Iranian peoples to donation, recruiting hundreds of Iranian donors.**
- **Our work: model for healthcare organization partnerships with community advocates from underserved populations to address health disparities.**

Next steps

- Apply this approach with other underserved populations.
- Partner with community advocates to address disparities in donor availability, especially for non-European ancestry patients.



- URD availability overall: only half (2,039/3,843, 53%) for CT & < 70% (604/889, 68%) for workup.
- Non-European ancestry pts: markedly worse availability (esp. if African, non-Black Hispanic, or Asian).