THE Alliance

Advancing Equity to Save More Lives in the Latino Community, Part II: Case Studies

TODAY'S PANELISTS

Ali Morales, RN
Director of Family Support Services
we are Sharing Hope sc
SOUTH CAROLINA ORGAN & TISSUE RECOVERY SERVICES

Maria Isabel Veve
Family Services Manager
DONOR ALLIANCE
Organ & Tissue Donation

Salvador Guerrero, MD
Family Resource Coordinator IV
DONOR NETWORK WEST
Heal a life through organ and tissue donation

Tuesday, September 19, 2023, 2:00pm – 3:30pm ET

Continuing Education Information

Evaluations & Certificates

Nursing

The Organ Donation and Transplantation Alliance is offering **1.0 hours of continuing education credit** for this offering, approved by The California Board of Registered Nursing, Provider Number CEP17117. No partial credits will be awarded. CE credit will be issued upon request within 30 days post-webinar.

CEPTC

The Organ Donation and Transplantation Alliance will be offering **1.0 Category I CEPTC credits** from the American Board for Transplant Certification. Certified clinical transplant and procurement coordinators and certified clinical transplant nurses seeking CEPTC credit must complete the evaluation form within 30 days of the event.

Certificate of Attendance

Participants desiring CE's that are not being offered, should complete a certificate of attendance.

- Certificates should be claimed within 30 days of this webinar.
- We highly encourage you to provide us with your feedback through completion of the online evaluation tool.
- Detailed instructions will be emailed to you within the next 24 hours.
- You will receive a certificate via email upon completion of a certificate request or an evaluation
- Group leaders, please share the follow-up email with all group participants who attended the webinar.

Deanna Fenton

Senior Manager, Educational Program Development & Operations

Need Assistance?

Contact Us via Zoom Chat, or
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786-866-8730

Meet Our Moderator

Ingrid Palacios

Multicultural Community Outreach Program Manager

New England Donor Services
Organ and Tissue Donation

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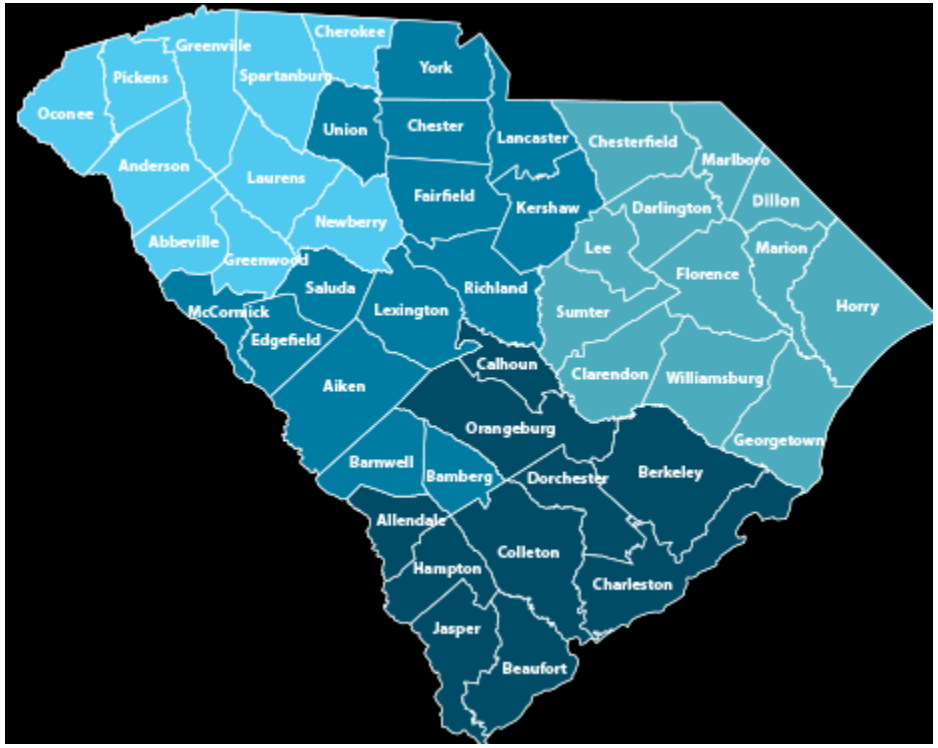
SOUTH CAROLINA ORGAN & TISSUE RECOVERY SERVICES

Advancing Equity to save more lives in the Latino Community, PART II: Case Studies

We Are Sharing Hope SC

- Founded in 1984
- Headquarters located in Charleston and have offices in Greenville and Columbia, SC
- 105+ employees
- Service entire state of SC (Except Edgefield and Aiken Counties)
- DSA serves ~ 5 million people
- 67 hospitals

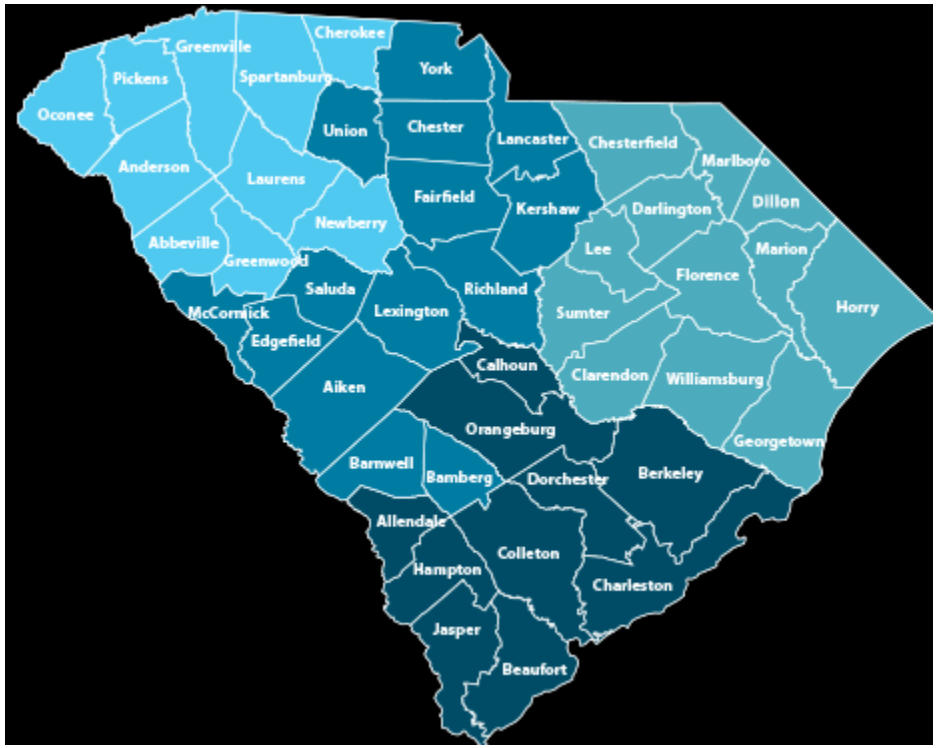


We Are Sharing Hope SC

we are Sharing Hope sc
SOUTH CAROLINA ORGAN & TISSUE RECOVERY SERVICES

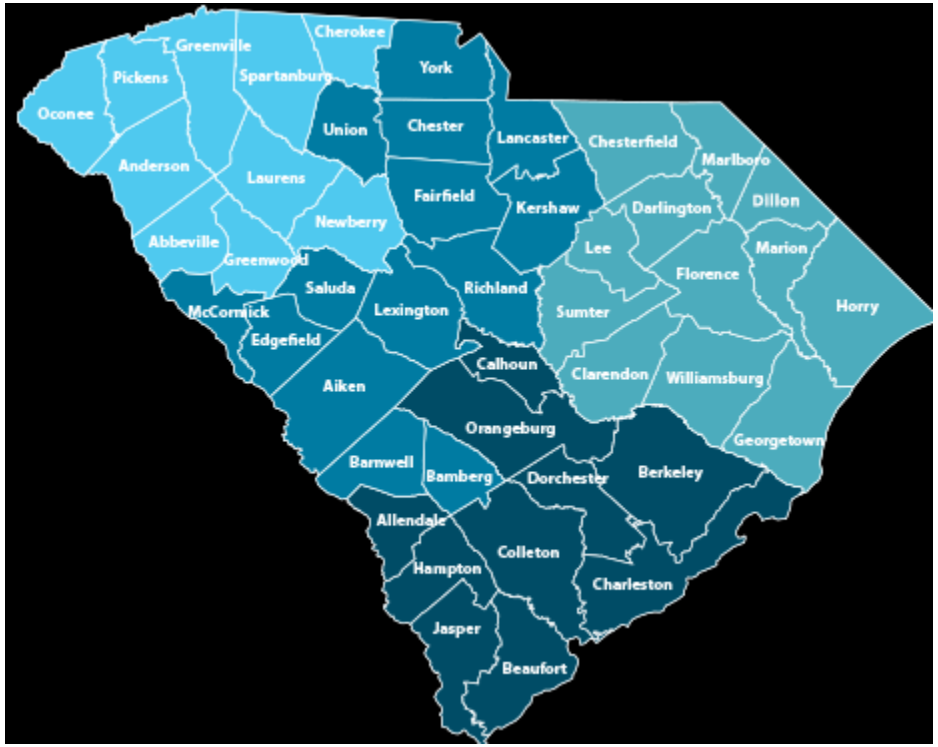
MISSION
Together we inspire our community, offer hope and change lives through the gift of organ, eye and tissue donation.

VISION
Every individual embraces organ, eye and tissue donation to save and enhance lives.



Hispanic Community in SC

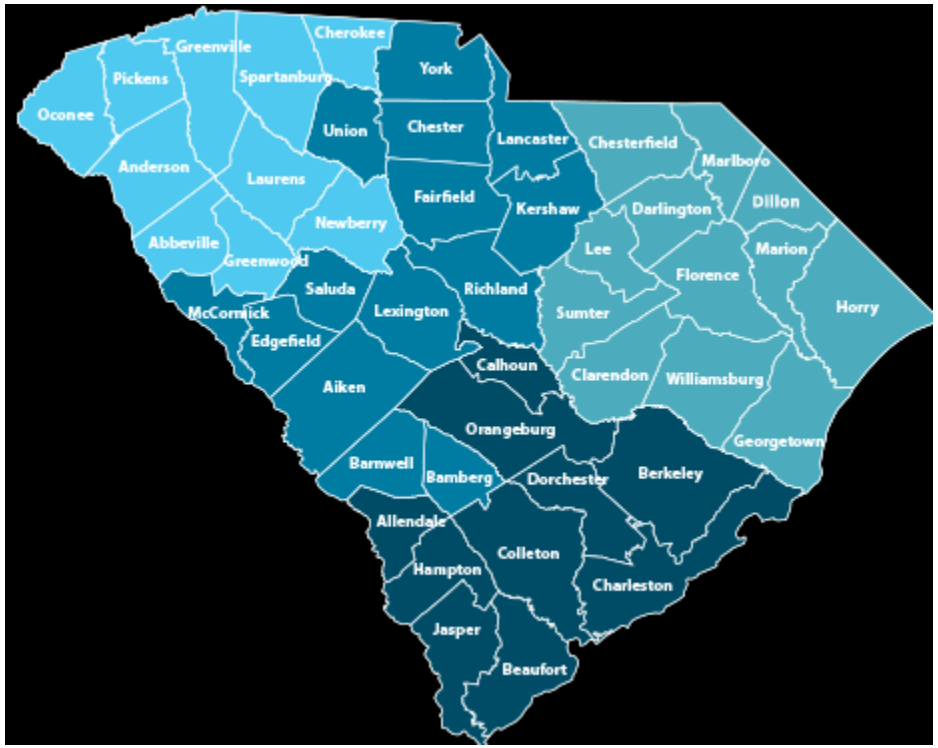
- Hispanics make up 5.6% of population (~350,000)
- Approximately 87,000 undocumented Hispanic immigrants in the state as of 2019.
- Education is highly valued in the Hispanic community. Hispanic students represent 9.5% of the student body (K-12).
- Hispanic-owned businesses represents the largest increase of all minority owned business which means this community contribute millions of dollars to the state economy every year.



* SC Commission of Minority Affairs 2019 & Valeria Aloe 2023

Hispanic Community in SC

- Many are uninsured (37%) or don’t have ongoing relationships with healthcare providers.
- Many challenges accessing health care and mental health services.
- Language barriers to healthcare is a big concern as well leading to significantly grim health disparities.



* SC Commission of Minority Affairs 2019 & Valeria Aloe 2023

Case Study: “Eduardo”

- 14 y/o HM presenting as a trauma patient. He was ejected from a vehicle during a rollover motor vehicle collision.
- He was transferred to higher acuity facility. Presented with a GCS3 on arrival. Multiple facial fractures, bilateral chest tubes, massive blood transfusion, sedation, paralytics…ALL THE CLINICAL THINGS!
- Focus on the family: LNOK are parents, Spanish-speaking. Younger brother is already a patient in the same PICU (dialysis patient).
- Significant socioeconomic challenges- no running water in the home which is partially why sibling was long-standing patient in the hospital for the last 9 months.

Case Study: “Eduardo”

Wednesday

- Huddle with HCT: Attending; only barrier identified was language related.
  - During rounds MD stated that due to pentobarb levels BDT was planned for the weekend, unless the family decided to WDLST before hand.
  - Neither Chaplains nor Childlife are involved at this time. Palliative involved.
- The hospital team shared that despite the use of interpreter, family would appear as if they understood, and then hours later they didn’t.
- MD shares that family typically takes a couple of days to process information before making decisions
  - Important to note that their long standing relationship with the family helps them understand their psychosocial needs.
  - Our work doesn’t always afford us months of time to get to know a family but time must be viewed as resource when assessing family readiness.
  - Referral mas made on day 2 of his admission.

Case Study: “Eduardo”

Wednesday

- Conversation Plan was to introduce BD and associated testing. These were going to be new concepts for the family.
  - BDT had not been initiated due to pentobarb levels.

*MD recommended for us to be introduced and potentially engage in donation conversations after their initial discussions. The reasoning was because they take several days to process information and make decisions.

- After the family meeting concluded, the family departed and the MD revised the plan for our involvement to give them a day to process.
  - Family had not made a decision to WDLST nor was there an inclination to transition to comfort.

Case Study: “Eduardo”

Wednesday

- What they were told was that BDT was planned for the weekend. They had many other relatives were going to arrive on Friday so they were receptive of this plan.
    - We were advised to engage in donation conversations the next day.

Thursday

- The following day, FSC was able to meet the mom. Dad was not onsite yet but a good first meeting occurred. Mom confirmed what the MD was ‘saying’; that “he would check to see if his ‘head’ was working.”
- Mom also identified herself as a woman of faith and is hopeful that her son will be ok even after they test his ‘head’.

Case Study: “Eduardo”

Thursday

- FSC determined that engaging in donation conversations at the time was not indicated. It was a good first meeting and rapport was being developed.
- BSRN and MD were updated and they expressed understanding and agreed it was a first good step towards what the next few days would look like.

Friday

- The following day the plan changed again: pentobarb levels had been evaluated throughout and a new send-out was being requested. MD was now considering not doing BDT unless the family requested it.
- MD also questioned the FSCs prior interaction with mom. He had recently met with her with the interpreter and according to MD she seemed to understand that he was brain dead. MD believes when family arrives they will elect comfort measures.

Case Study: “Eduardo”

- The MD insisted FSC approach the family. Despite the FSC being a Spanish speaker, a hospital interpreter joined in so there was no confusion about what the parents were communicating.
- Mom stated that she was being told she had to make a decision that day once family arrived. She was also saying she was not ready to make any decisions.
- Mom further stated that she DID want BDT to see what the result would show.
- FSC explained how sedation levels would need to evaluated, that would require time. Mom is asking for confirmation of BD.

Case Study: “Eduardo”

- FSC reassured mom that he and the interpreter would communicate to MD that she in fact wants BDT.
- But FSC still transitioned into donation conversations.
- She asked if a transplant would save his life. A lot of support and education had to be provided to ensure she understood and could distinguish “Eduardo’s” potential donation pathway vs. his brother’s transplant pathway. (His brother was not eligible for transplant due to other health factors)
- Mom said she would consider it but still insisted she wanted BDT.
- MD was frustrated again reiterating that mom knows he’s BD.
- The interpreter also spoke up confirming that this was the mother’s request.

Case Study: “Eduardo”

- MD stated he would meet the mom again.
- 30 minutes later he informed everyone that family was ready to WDLST immediately.
- Once again, FSC and interpreter returned to the room and inquired as to their decision.
- Mom was very emotional and said she was told she had to make a decision and made it. She wants it over with and wants her son at peace. She declined donation.

Poll Questions

Q1. Based on the general psychosocial make-up of this family, what are some resources they would benefit from?

A. Language services
B. Spiritual care/ chaplaincy services
C. Child-life services
D. All of the above

Poll Questions

Q2. In crisis moments, What makes people feel unsafe?

A. Unpredictability
B. Unfamiliarity
C. Loss of control
D. Lack of support systems with no outlet for frustration
E. All of the above

Poll Questions

Q3. Letting the family decide whether BDT should be done is best practice:

A. True

B. False

Starting the Climb is the first Step …

Maria I. Veve
Family Services Manager
Donor Alliance

DONOR ALLIANCE
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Colorado & Wyoming

Malcolm Baldrige
National Quality Award
2018 Award Recipient

MISSION

Donor Alliance saves and heals lives through organ and tissue donation and transplantation

VISION

Maximizing all donation opportunities

CORE VALUES

Integrity
Leadership
Excellence
Accountability
People First

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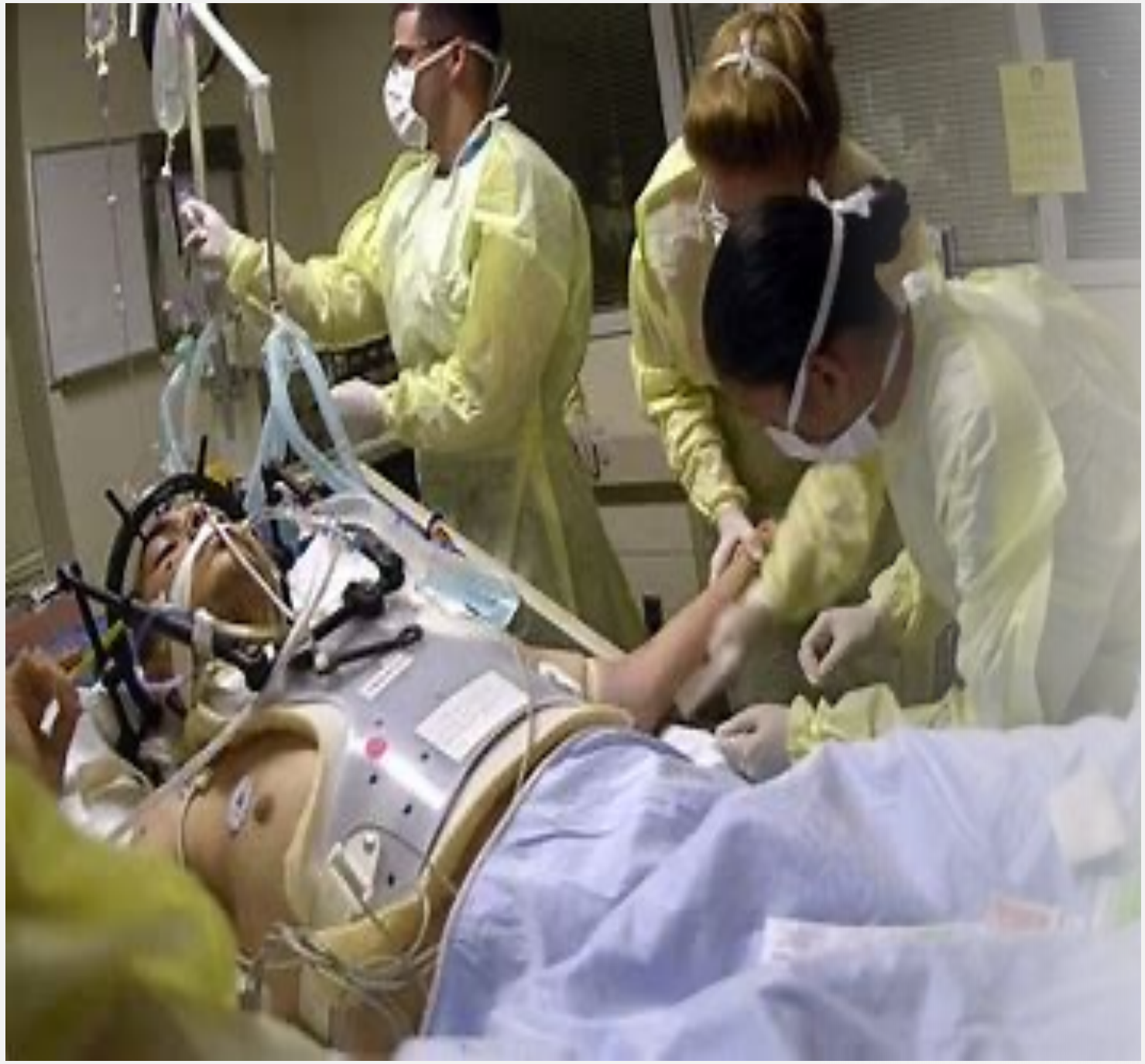

“Jose”

- 45 yr H/M admit to Trauma/ER with a closed head injury after being hit by a car.
- Jose’s friends from a local homeless shelter were onsite. They spoke Spanish only and shared that he was undocumented with a possible estranged spouse, unknown location.
- Per hospital interpreter the friends were very scared to talk, humble and just wanted to be present so Jose would not be by himself.

"Jose"

- Hospital Visibility: Family Services and HD arrived onsite after initial referral
- RN introduced Bilingual Family Support Coordinator (FSC) to friends.
  - FSC was also able to begin building a relationship with the friends and interpreter.
- Hospital Huddle with Health Care Team and Interpreter took place after introductions. ***Physician announced 24 hr deadline following BD testing.***

Day 1 Next Steps

- FSC/ HD conference call with AOC to discuss next steps
  - Diligent search initiated to find potential estranged spouse/family
  - Decision for Organ Recovery Coordinator remote monitoring of Jose
  - FSC/HD to provide conference call outcomes to the hospital

“Jose”

- Family located and notified of Jose’s condition via telephone by the physician with the interpreter.
- The estranged spouse and two daughters were out of state and wanted to drive to hospital prior to making any end-of-life decisions.
- <u>The physician agreed to an additional 24 hours!</u>

“Good News and Bad News!”

DONOR ALLIANCE Organ & Tissue Donation

DONATE LIFE Colorado & Wyoming

Malcolm Baldrige National Quality Award 2018 Award Recipient

DonorAlliance.org | DonateLifeColorado.org | DonateLifeWyoming.org

"Jose" First 24 hours:

- Immediate onsite presence and Health Care Team discussions.
- Introduction to friends and information gathered of potential family
- Hospital Huddle with Health Care Team after introductions
- FSC/ HD Conference call with AOC
- Diligent search initiated to find potential family.
- Estranged spouse and two daughters found. The physician with interpreter informed them of Jose's condition.
- Additional 24 hours provided.

- The estranged spouse requested more time for daughters to see their father prior to the organ and tissue donation.
- The family did not have funds, so they wanted to seek information on burial assistance which hospital provided with County Assistance Program.
- Hospital extremely generous and provided additional 24 hrs. for the family to drive from nearby state.
- BD declaration completed

The Arrival Day….

The estranged spouse, girls, and close family friend arrived the third day. They spent a few hours with "Jose" prior to completion of donation documents.

FSC continued onsite presence.

"Jose" was a very strong man.

He was stable all the way to the operating room.

Preserving Donation Opportunities

- **Day 1: Starting the Climb is the First Step**
- **Day 2: The First Step Led to Another Day**
- **Day 3: One Step at a Time Led Towards the Top of the Climb, *Saving and Healing Lives***

“Jose was able to save and heal many lives..”

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Poll Questions

1. What is the importance of providing a hospital huddle?

A. Communication

B. Relationships

C. The ability to provide dignity and respect to Jose when in dialogue with the hospital/ Health Care Team

D. All of the above

Poll Questions

2. A Bilingual FSC is always needed in these scenarios.

True or False

Poll Questions

3. What are other types of communication when there are language barriers?

A. Body Language, Facial Expression, Appearance

B. Hand shake

C. Interaction with others

D. Speaking slowly in English

Culturally Competent Best Practices to Care for a Hispanic Family

A Guide to Help Healthcare Professionals Best Support Hispanic Families During End-of-Life and Create a More Compassionate Donation Experience.

General Guidelines for the Coordinator	**Review the Hospital Profile: verify demographics-patient name, date of birth, MRN#, country of origin, language services needs- know your patient!** Check Registry status **Huddle with hospital care team and gather as much information as possible about the family – LNOK/AP, decision maker, key family members involved in hospital conversations. Know your family!** Identify family needs and act as a liaison between family and hospital team. This helps build rapport. **Continuity of care by the same coordinator is beneficial to help build trust and rapport. Maintain assignments if at all possible.** International calls- while cellphones are common, some rural areas in various Latin American countries still rely on one community phone. Whomever answers the phone call will get the family to call you back but you must ensure to get a time-frame of that return call.
Key Information on Cultural Values and Belief Systems	**Wide diversity due to expansive countries of origin. We are not all the same!** Assess any language interpretation needs but don't assume these families don't speak English. While Spanish is predominant language, there are also indigenous dialects. **Strongly influenced by respect.** Direct eye contact may be avoided with someone perceived to have more authority, i.e. doctors. **Silence may mean disagreement. Encourage families to speak up**. "Culture of yes"- nodding of the head 'yes' does not mean agreement. Encourage families to verbally define what the gesture means. **Authorization requires clear and precise understanding. Provide informational material and donation forms that are in Spanish or bilingual.** Spokesperson and decision-making can usually be head of household which traditionally is father or oldest male but important decisions may require consultation amongst the entire family. English speakers may be incorporated into the decision-making process.
	Mothers, on the other hand, are revered for cultural wisdom and life experiences. Family structure is usually matriarchal.
The Two Surnames (Apellidos)	**A surname is a hereditary name shared by all members of a family.** In Spanish speaking countries we have two, and the rule of the "last one" is often times where the confusion arises. **The first surname addresses the paternal family line. The second, the maternal line.** When in doubt get clarification of whether it is paternal and once the name is confirmed double check your registry.
Support Systems	**Pre-huddle with language interpretation services even if your coordinator speaks Spanish, especially during formal authorization and med/soc. interviews. Interpreters benefit from time to prepare for the conversation. Introduce them to some of the verbiage they will hear.** Chaplain or spiritual care services are usually welcome. Inviting their spiritual advisor into planned meetings is a good way to build rapport because there is trust in this individual. **Expect large numbers of visitors because of the strength in the collectiveness of the culture. Usually quiet group gatherings.** Expect the family to await the arrival of relatives that live outside the US. They may request days to allow time for their input. If other relatives cant arrive discuss virtual videoconferencing (e.g. What's App or FaceTime) options to be inclusive of the collective family structure.
Children	**Children have sometimes been used as interpreters for adults when needing to navigate healthcare and education systems. This disrupts the parent-child relationship and forces them to mature quickly resulting in added stress on the child. Use hospital based interpreter at all times.** Include child-life services as an added layer of support and also empower the child to participate in memory making activities.
Check for Bias!	**Monitor for bias as part of your huddle; both personal bias and the team's.**

Relevant Resources

Patient's Spiritual and Cultural Values for Health Care Professionals Handbook

https://www.spiritualcareassociation.org/resources.html This content is used with the permission of HealthCare Chaplaincy Network

"The Dangers of Using Children as their Parents Interpreters" Dynamic Language 2019. https://www.dynamiclanguage.com

Guidance document created by Salvador Guerrero (*Donor Network West*), Ali Morales (*We Are Sharing Hope SC*), Ingrid Palacios (*New England Donor Services*) and Maria Veve (*Donor Alliance*).

A Special Thanks to Our Panelists

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THE Alliance | Conversation Series

DIVERSITY, EQUITY, AND INCLUSION FOCUS