Advocacy Town Hall
Wednesday, August 5 at 2:00 pm EDT
To Ask a Question

**OPTION 1:** Click on the hand icon to notify the organizer that you have a question.

**OPTION 2:** Type your question into the *Questions* box on the control panel.
Campaign – Two Parts

- "Meetings" with federal legislators
  - CEOs/Executive Directors
  - Board Members
  - OPO Staff
  - Supporters

- Emails
  - OPO staff
  - Board members
  - Supporters
Two Overarching Points

• AOPO and the Organ Procurement Organization (OPO) community supports valid and continually improving performance metrics, that are based on sound data. Unfortunately, the proposed metrics fail to meet these standards.

• The U.S. organ donation and transplantation system is one of the best in the world, if not the best, but we can do better.
• **Performance Threshold**
  - Under the proposed rule, the bar to “pass” is arbitrarily set at the top 25\textsuperscript{th} percentile without supporting rationale ensuring 75\% of OPOs would not meet the metrics and could be subject to decertification.
  - Decertifying up to 75\% of OPOs in a given year would destabilize the system without an identified path for OPO performance improvement potentially leading to loss of lives.

• **Recommendation:** Establish a performance threshold for the donation and transplantation rate metrics based on a specified standard deviation from the mean.

• **Rationale:** Using a standard deviation performance threshold would more accurately and fairly assess OPO performance. It balances the need to incentivize continual performance improvement while establishing a rational basis for the threshold as supported by the data and valid statistical methodology.
• **Use of Death Certificates to Calculate Donor Potential**
  • Studies show that 30% to 60% of death certificates inaccurately report cause of death.
  • Death certificates do not necessarily reflect whether a patient was eligible for donation. The certificates show primary cause of death but inconsistently document secondary conditions, such as if the deceased person was COVID-19 positive or had metastatic cancer, which would make them ineligible for donation.

• **Recommendation:** Use inpatient ventilated deaths as the data set for donation rates.

• **Rationale:** A potential donor must be on a ventilator in a hospital at the time of death for organ donation to occur. The calculation of a donation rate should include only these inpatients for the most accurate performance metric.
Talking Points – One Metric

• The Organ Transplant Metric Essentially Duplicates the Donation Rate Metric
  • As both metrics share the same denominator, i.e. a calculation of donor potential based on
dead certificates, in essence both metrics measure the same thing and in effect there is only
one OPO performance measure not two.

• Recommendation: Retain the current Observed to Expected (O:E) Yield measure
as the measure of organ transplantation rates.

• Rationale: The observed versus expected ratio calculates the number of organs
expected to be transplanted from a given donor (based upon data from actual
donors) and compares it to the number of organs the OPO actually provides for
transplant. If the ratio is 1.0, the OPO is performing as expected, if the ratio is >
1.0 the OPO is exceeding expectation, and if the ratio is < 1.0 the OPO is
performing below expectation. Retaining this metric would also satisfy the
statutory requirement for OPOs to be evaluated based on multiple metrics. The
data is independently reported, verifiable, calculated, and widely supported by all
stakeholders in the donation and transplantation community.
Meeting Tips

• Be authentic, tell your story
• Don’t speak in jargon
• Familiarize yourself with the talking points – practice, practice, practice
• Don’t be afraid to say “I don’t know”
• You don’t get what you don’t ask for
• Remember to say “Thank You”
Volunteer Mentors

- **Jeff Orlowski** – President & CEO, LifeShare of Oklahoma
- **Joe Roth** – President & CEO, NJ Sharing Network
- **Kathy Lilly** – Executive VP – LifeLink Foundation
- **Kevin Cmunt** – President & CEO, Gift of Hope
- **Lori Brigham** – President & CEO, Washington Regional Transplant Community (WRTC)
- **Alex Glazier** – President & CEO, New England Donor Services (NEDS)
- **Bobby Howard** – Director, Multicultural Donation Education Program, LifeLink
- **Karen Kennedy** – Director, Clinical Services, The Living Legacy Foundation (The LLF)
- **Marion Shuck** – Director, Family Services and Community Outreach, Gift of Hope
- **Michael Kenney** – Legal & Legislative Advisor, Center for Organ Recovery & Education
- **Sara Pace Jones** – VP, Development & Referral Services, Donor Network of Arizona
OPO Approach to Advocacy

Jeff Orlowski
President & CEO
What is “Advocacy”?

- Advocacy is defined by Merriam-Webster as:
  - the act or process of supporting a cause or proposal
  - the act or process of advocating something

- When we as an OPO or as a community engage in advocacy, we generally are supporting causes, proposals, or policies that enhance our ability to do our lifesaving work or against things that might impede our ability to achieve our mission.

- OPOs can conduct advocacy activities at both the Federal and the State level.
Why should “my OPO” be actively engaged with advocacy?

• As the designated OPO for your DSA and the states or portions thereof, your OPO is uniquely positioned as...
  • THE expert resource on matters pertaining to donation and thus uniquely positioned to advise and be a resource to your delegation
  • A critical service provider to your delegation’s constituents
  • A non-profit employer

• The organization primarily if not uniquely affected within your delegation’s district.

• In short, they will want to hear from your OPO and your OPO is largely the only constituent organization that can provide expert help in the organ and tissue donation space, and...

• If you don’t advocate for your OPO, who will?
Who Do You Engage?

• At the Federal level, in most cases, your engagement will be with one or more of the following in the Representative or Senator’s office:
  • Health Staff (most commonly)
  • Senior Staff
  • District Staff (“home team”)
  • Congressional Member

• At the State government level, much more engagement will be with the Member themselves.

• My comments from here will focus on U.S. Senators, and U.S. Congresswomen and Congressmen.
• If you haven’t had contact before, schedule a visit to DC and introduce both your organization and your key points of contact. Include 2-3 key OPO staff in the meeting such as other senior leaders and/or front-line staff.

• Realize you will likely have limited time, may have to meet in the hallway or a reception area, and your audience won’t have the time to dive deeply into the nuances nor will they likely know what an OPO does.

• Keep it simple...have a few talking points (I prefer three to four maximum); your purpose is to inform, not make them experts!

• Offer follow-up, additional resources, and have something to leave behind that reinforces your message and steers them back to you if they want to do research.

• ALWAYS make sure they know you’re a resource to them and just not there asking for their help.
How, What, and When – If You Have an “Ask”

• **Whether you have visited before or not, you will often have an “ask”**.
  • An ask may be direct support for your OPO (currently, a letter to Azar asking for a delay in implementing new OPO metrics).
  • An ask may be support of a related item (historically, support for the immunosuppression bill for example).

• **Be clear and direct about what you are asking for.**

• **Be clear about why this is important to your OPO.**

• **Illustrate why this is important to your service area and the Member’s constituent voters.**

• **Always allow time for questions.**
How, What, and When – Staying in Touch

• Send a thank-you.

• Add them to your OPO newsletter and annual report distribution.

• Visit their in-district office.

• Invite the Member and their District staff to visit your office.

• Make follow-up visits to DC office at least annually (at LifeShare we are committed to twice per year), even if you have no “ask”.

• Engage your Board Members, Volunteers, and other stakeholders...many of them have contacts and most have a story to tell.
Other Thoughts

• AOPO provides a lot of support and resource to help you;
  • AOPO – Steve Miller
  • Strategic Healthcare – Devon Seibert-Bailey and Paul Lee

• A number of LRAC members are available to help advise or mentor.

• At LifeShare, we have retained a DC-based Advisor who makes more frequent contact with Members and their staff, helps us navigate to key Committee staff (i.e., Finance or Appropriations), and collects information for us.
Advocacy Meetings

Devon Seibert-Bailey
Senior Vice President
Remember...

- Lobbying is simply meeting with your elected representatives and their staff to communicate what is important to your OPO.

- Remember to stay concise and be direct with the “ask.”

- Keep It simple.

- You and/or your staff are constituents, they serve you!
Requesting the Meeting

- **Using sample e-mail to send to district or state staff person.**
  - Be sure to mention if you are a constituent.
  - List every hospital in the Congressional District that you work with (no need with Senator).

- **Be persistent, if you haven’t heard back in 2-3 days reach back out.**
  - Remind them in follow up e-mails that your work impacts all their constituents.
  - You can reach out to DC staff such as the scheduler or chief of staff if need be.
  - If having difficulty scheduling, reach out to [Devon.Seibert-Bailey@shcare.net](mailto:Devon.Seibert-Bailey@shcare.net) or [Britnee.Dorn@shcare.net](mailto:Britnee.Dorn@shcare.net) for assistance.

- **Provide multiple option for dates and times of the meeting.**
  - It is okay if they only give you a 30-minute time slot, that means they are trying to fit you in.
Prep Yourself

• Have your one-pager ready for the meeting for the Member of Congress or staff to follow along with your presentation.

• Know a few facts about the Member of Congress.
  • Go to their website ahead of time, do they have a connection to healthcare?

• Likely will have a staff member with them.
  • If staff is from the “district” will be less familiar with regulatory process, if DC based staff will have more knowledge.
Know Your “Ask”

• Before the meeting begins, fully review bullet points and give a direct, concise summary of the issue.
  • Use layperson language.

• Introduce yourselves, state if you live in the district.
  • If not state which hospitals are in the district and state that your work impacts all their constituents.
  • Include staff members or volunteers who are in the district if possible in the meeting.

• Be very direct with your “ask.” Members of Congress and staff will want to know exactly why you are meeting with them.

• Remember to tailor your presentation to the office.
  • Republican or Democrat? Do they sit on an important Committee?
  • Do they have a health care background or a family member in health care?
  • Is it a rural or urban district? What are the demographics?

• Repeat your “ask,” ask if they have any questions, and thank the Member of Congress and their staff for their time.
After the Meeting

• Be sure to take note of the staffers that were part of the meeting.
  • Ask for contact information.

• If there were any questions or issues that required follow-up, email or call the staff member to address them.

• The next day, send an e-mail to each staff member thanking them for taking the time to meet with you and for considering your “ask.”
  • If Member agrees to send a letter, send to the staff member immediately after the meeting.

• Follow up a week later with staff in inquire on the status of the “ask.”

• Reach out to Steve Miller at AOPO to give an update on how the meeting went.
To Ask a Question

**OPTION 1:** Click on the hand icon to notify the organizer that you have a question.

**OPTION 2:** Type your question into the *Questions* box on the control panel.
Thank You!