

The Transplant Roundtable met for 2 hours Jan 28th. The following are informal notes taken by TRIO's representative to the Roundtable during that audio conference session:

1. **UNOS** presented a PowerPoint showing TX results.. .

- Hearts and lungs are basically flat.
- Many needing hearts are candidates for LVADs and may not need a transplant or the transplant can be postponed.
- Death rates of recipients are down by about 1% across all organs. UNOS attributes this to Centers doing a better job.
- UNOS is discussing ways to move long-term in-actives off the list, as they are people who will never get transplants (i.e., cancer patients).
- 2009 was the best year for living donation. 2010 will be down slightly. This is assumed to be because of the recession. People can't afford to be donors (loss of wages, travel expenses, etc.).
- Donations after cardiac events are up slightly. This is the type of donor that was originally used before brain death became the primary determinate of death.
- In 2004, the majority of kidney transplants were from living donors for the first time. This trend continues.
- Use of extended donors' (older) organs has increased.
- Half of candidates on the list will never be transplanted, as they have medical issues which prohibits transplants (inactives) or will die (due to lack of organs) before receiving a transplant.

2. **Congressional Organ and Tissue Caucus** (House).

- There is discussion of making it a bi-cameral caucus (i.e., House and Senate).
- Many of the prior participants have retired or been defeated, so the TX Roundtable will draft a letter to be sent by current caucus members to all of the other members of Congress, asking them to join the Caucus
- The Roundtable will draft a letter for all TX Roundtable members' signatures delineating our legislative priorities for this session of Congress.
- Who will be the new champion of organ donation in Congress?
- Possible Roundtable event to honor out-going representatives who were influential and supported of organ donation.

3. **Immunosuppressive Bill**

- Two days before Congress ended in December, the Congressional Budget Office re-scored (figured out the cost) of the Immunosuppressive Bill. This version of the bill would have given all uninsured kidney recipients life-time immunosuppressive coverage.
- CBO scored it at \$100,000,000 over 5 years (really only 3 years, since Healthcare Reform would kick in in 2014). This down from \$800 million previous score.
- It does NOT take into account the additional taxes that would be collected from kidney recipients who could go back to work and contribute taxes to the budget. We can't get CBO to include this factor.
- In addition, we believe that CBO overestimates the number of people who would actually qualify for this benefit – anyone who was already on Medicare due to age or disability and anyone who had insurance or Medicaid would not be covered under this bill. So the number of people who need lifetime coverage is relatively small.
- Representative Camp has been approached to take a leading role in this legislation.
- The Roundtable is pushing to have the comprehensive immunosuppressive bill introduced. This bill covers ALL kidney recipients who have no drug coverage, even those transplanted previously.
- If the comprehensive bill won't fly, then we would go back to the bill which would cover only new kidney recipients, after the passage of the bill.
- In theory, this issue will be moot when Healthcare Reform takes effect in 2014, so this is a stop-gap measure.
- Representative Dorgan is gone – he was a major champion of organ donation and was on the House Appropriations Committee, which put him in a great position to help our issues.

4. **RELIVE update**

- Funded by a grant from NIH, which will probably NOT be renewed due to funding.
- Program is database of living donors and their long-term results and health.

5. **Insurance coverage for living donors**

- This would be a government program under Medicare.
- It would provide subsidies to living donors who could not get insurance.
- No action in Congress on this – the response to most things in Congress right now is 1) “we can't afford it, as we have no money” or 2) “just wait until 2014 when healthcare reform kicks in.”

6. **Tax credits for living donation**

- Up to \$10,000 Federal tax credit for out of pocket and loss wages incurred by living donor. This credit would be refundable (i.e., it could result in a refund).
- An informal survey of about 10 large centers said this credit might increase living donation at their center by 30%.
- Credit would still be a cash flow issue for low income people because the credit would not be received until the following year after donation, when their tax return was filed.
- Roundtable is going to survey the states that already have a deduction/credit for donation and see how big of a revenue loss this really would be.
- See 3rd bullet under # 5

7. Family Medical Leave Act (FMLA)

- Trying to amend FMLA to include living donation as an FMLA covered activity.
- This is a no cost program to the Federal Government or the employer (unless they hire someone to take over the FMLA taker's work while the FMLA taker is on leave).
- Roundtable will work with US Chamber of Commerce

8. World Kidney Day is March 10.

- There was discussion of fly-ins from around the country for various organizations. Many organizations have already scheduled their fly-ins for dates other than WKD.
- PKDF will have their Fly-In March 13-15. See www.pkdcure.org.

9. Healthcare reform

- Department of Labor is surveying the "usual" employer coverage provided to assist in determining the contents of a basic policy.
- HHS is working on the definition of "essential health benefits". The Roundtable will work with HHS to ensure that ESRD, all types of transplants, and immunosuppressive medications are included in "essential health benefits" definitions.

10. Vascularized Composite Allografts

- DOT has jurisdiction of organ donation
- USDA has jurisdiction over tissue donation
- Something needs to be worked out between them when transplants include both types

11. Medical School Curriculum – HRSA needs funding for this. See #5, bullet 3

12. Donor Medal

- UNOS is commanded by law to create the medal according to the specifications in the law, which was passed several years ago.
- However, UNOS has to raise money separately to create the initial batch of medals.
- Medals would be sold to OPOs for presentation, which would make the medal fund self-perpetuating.
- UNOS has not identified a source for the initial funding.

13. OPO and Transplant Center Conflict Resolution

- I couldn't hear this part.

14. Medicare for Pancreatic Islet Cell Transplants

- I don't believe Medicare pays for this now, as I believe that it is still in the research stage for Type 1 diabetes.
- There were 41 centers doing islet cell transplants but now there are 8, which is hurting research.

15. State Transplant Issues

- **Arizona** issue is still on-going. The House, Senate and Governorship are all Republican-controlled. They are all looking for ways to cut the budget for Medicaid. See #5, bullet 3.
- **Illinois, New York and California** Due to state budget issues, they are looking to follow Arizona's lead.
- **Texas** is looking at eliminating ESRD and transplant from its Medicaid program.
- **Washington** is looking at eliminating pharmacy coverage, which would "save" \$3.2 million and affect 49,000 people.
- The Roundtable is going to create a White Paper to be used by opponents in each of these (and any other) states to assist them in defeating the deletion of these services from the programs.
- We discussed having the Roundtable take a lead on this but decided that it is perceived as a "states right" issue and National organizations should not be trying to stomp on the states.

16. Living Donation Collaborative

- HRSA is looking at best practices for organ utilization – paired donors, multiple donor exchange, etc.

17. DOT budget

- Current proposal in the House is to roll back all discretionary spending to 2008 levels. This would result in a 15% reduction for HRSA/DOT.
- Roundtable will be pushing for 2010 level in 2011 and asking for more.
- 2012 request from Roundtable will be 2011 + more.
- See #5, bullet 3