

TRANSPLANT ROUNDTABLE

12:00 NOON – 2:00PM

JANUARY 18, 2012

MEETING AGENDA AND NOTES

AS TAKEN BY JIM GLEASON

- I. Roll call/ lunch (compliments of ASTS).
 - a. Brief review of organ donor / transplantation data (UNOS)
Inactive waiting list reporting numbers discussion as published in UNOS weekly report.
Active, inactive and multiple listed numbers are now given to clarify the actual number of individual patients awaiting transplant - today this is approx. 72k vs. the overall number of listed of 112k per Bill Lawrence)

- II. Congressional Issues.
 - a. Immunosuppressive drug coverage extension legislation. (ALL)
Progress being made. Steadily adding (ie.10-12) co-sponsors. Support is there but cost offset still needs further confirming data. Keep up contacting legislators. Action pan needs to be sent out. Urging more organizational “fly-ins” to communicate the message to individual legislative offices.

 - b. FY '12 & '13 Budget/ Approps – HRSA Div. of Transplantation. (ALL)
Expecting a “frightful year” ahead in terms of funding. General discussion on appropriation individuals to target with our message. Add job focus on our message to address the area of most interest today. Doubt increases are possible, but need to fight to at least fund the same level. Letter being drafted accordingly.

 - c. New living donor proposals – Medicare / HRSA lost wages funding. (UNOS)
Bill Lawrence: subject is for lost wages financial support for living donors (compliant with NOTA). Informal survey of centers showed that for hourly waged donors they felt that 25% to 30% increase in living donors if one month’s lost wages could be offered. Suggest that U of Michigan’s current program might be expanded to include lost wages as a test to see if this works, as one example. Travel and subsistence is already covered. Significant savings of \$240k from that increase in living donation vs. continued dialysis was forecast. UNOS leadership supports this. Asking Roundtable to see if this group would take it up as a good cause. (Bill to send out paper)

 - d. FMLA and guaranteed leave for organ donation. (NKF/NATCO)
Not aware of any legislation currently in consideration. Not a 2012 focus. Maybe related to flextime as an alternative.

 - e. Tax credits for living donor expenses (HR 2755 – Kissell) (NKF)
Still under study before suggesting action by this group. Includes lost wages but most activity is at the state level. Pending more investigation. Not sure of what committees are looking at this.

- f. Insurance coverage for live donors. (ASTS)
Brief explanation of the issue. This should not be an issue given current legislation already enacted. Watching out that no loopholes arise. NATCO watching closely.
- g. Organ & tissue donor registry center (HR 3514 – Clay) (NKF)
NKF not really getting behind this as a priority. Asking the question on this. Original bill didn't have "living donors" in it. Topic raised as "trial balloon" for discussion. Not much resulted.
- h. Kidney Caucus and potential events.
Some discussion about the "kidney caucus" - undergoing reorganization. They held a good September event last year focused on dialysis
- i. Congressional Organ & Tissue Caucus and potential events.
How do we want to work with this caucus? . Suggesting topics for future events for an open staff briefing this coming September. How to keep them encouraged and gaining new members? Bill L to reach out and offer Roundtable interest support to the caucus.

III. Regulatory Issues.

- a. Health reform—definition of "essential health benefits." (ASTS/AST/NKF)
Brief overview offered. HHS planning to offer proposal for public comment "soon." Looking at existing state plans as models, most of which cover transplant. But Arizona's experience shows an area of concern (also Oregon). Does this rise to the level of a Transplant Roundtable letter? Left as an open question.
- b. Vascularized composite allografts—HRSA v. FDA Oversight. (UNOS)
UNOS chartered to write the policy, a very complex issue with no precedent and very different than organs. HRSA says to UNOS, start small but do it. Asking for a Roundtable letter of support. Concerned raised about lack of funding for this area. Need HRSA to address the cost, followed by funding source. Also need better definition of what HRSA really wants UNOS to do. This really isn't about organ transplant centers, but rather an unknown number of neuro and orthopedic, etc programs that have been in operation for over 30 years now. Decided to put it in the letter on allocations.

IV. State Issues—Medicaid. (ASTS / AST)

No specific discussion beyond that mentioned above under III.a

- V. Review final 2012 action plan and priorities.
Bill to send out state report. Appropriations letter to be drafted, to include the VCA topic above. Other actions and sign in sheet will be sent out.

VI. Adjourn.

Future meetings are scheduled based on requests/interest, so no date is set here.