

UNOS Member Survey 2011

Open-ended Comments

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UNOS Member Survey 2011- Open-ended Comments

Informational Needs of patients, living donors, or non-transplant health professionals

Question: Are there informational needs of patients, living donors, or non-transplant health professionals that are not currently being met? If so, please explain.

- 1 Appropriate explanation of SRTR data and what it means at a simple patient level. Dramatic disclaimer for payors and the why to use SRTR data and what to use it form
- 2 .
- 3 A help desk or useful (available to transplant centers) phone number for 24 hour needs.
- 4 ability to breakdown data by DCD donors would be helpful
- 5 Brochures are on back order frequently
- 6 Brochures in Vietnamese would be helpful.
- 7 data! more self-serve report capabilities should be implemented.
- 8 Educational DVDs by organ
- 9 explanation of ECD, DCD and CDC high risk donors in pamphlet form
- 10 financial resources for living donors
more discussion on proposing reimbursement for living donors
- 11 history and archival of polices and procedures so you can research practice changes
- 12 I am not aware of any
- 13 I am not sure
- 14 I cannot identify a need at this point
- 15 I do not currently access this type of data.
- 16 I find very little educational material on Pancreas transplant.
- 17 I would like to see more in person support groups for deceased donor families, transplant recipients and living donors. I live in a rural area where all recipients have to travel for their transplant and then when they get home there is no formal support group type setting for them to interact with other transplant recipients. Same for bereavement support for the deceased donor families there is no support group for them. There is no support group type setting for folks who are listed for transplant or beginning the living donor process either...bottom line is more information and more support is needed.
- 18 I would recommend that UNOS develop a letter, similar to the one transplant centers are required to reference and include in all candidate patient correspondence, for donors. I would also recommend UNOS provide centers with another HIPAA memorandum so that we can get information easier from the recipient and donor PCPs.
- 19 Info about chain donation
- 20 Information needs are being met.
- 21 Information regarding international transplants
- 22 make it easier to find info. If I didn't know where to look, it would be very difficult to find various resources that are available online (e.g., thru the OPTN site). Policy and bylaws are difficult to navigate because some info is in less-than-obvious sections.
- 23 material on Paired Exchange is needed
- 24 more information available in Spanish
- 25 More information for living donors would be beneficial. Also success/outcomes at various centers should be easier to find.
- 26 More information regarding living donation

- 27 More standardized information for patients would be helpful. Topics such as high risk donors, HLA typing/matching, etc would be helpful.
- 28 na
- 29 NA
- 30 NA for me
- 31 Need a review of all these resources I didn't know about.
- 32 Need EASY TO USE web page with patient, donor, and professional information.

N
33 need English as second language VERY basic transplant information - lots of pictures & basic simple information.

- can use this for pediatric, MRDD, low literacy patients as well
- 34 need for various languages other than Spanish- ex: Russian
- 35 need more info about good Samaritan donation
- 36 Need standardized education info for What a High Risk Donor Is and ECD SCD donors.
- 37 Need Vietnamese language materials.
- 38 No
- 39 no
- 40 no
- 41 no
- 42 no
- 43 no
- 44 No
- 45 No
- 46 No
- 47 no
- 48 no
- 49 no
- 50 no
- 51 No
- 52 no
- 53 no
- 54 no
- 55 No
- 56 no
- 57 No
- 58 No
- 59 no
- 60 No
- 61 No

- 62 no
- 63 NO
- 64 No
- 65 No
- 66 No
- 67 no
- 68 No
- 69 No
- 70 No!
- 71 No.
- 72 none
- 73 None
- 74 none
- 75 none
- 76 None
- 77 none known.
- 78 None that I am aware of at this time.
- 79 Not at this time
- 80 Not at this time.
- 81 Not sure
- 82 Not that I am aware of.
- 83 Not that I can think of
- 84 Not that I know
- 85 not that i know of
- 86 Not that I'm aware of.
- 87 not to my awareness
- 88 Not to my knowledge
- 89 Opposite - In the interest of communication, UNOS/OPTN is requiring too much of the transplant center.
- 90 Paired Exchange patient information for patients at low health literacy - grade 4
- 91 Patient information hand outs are often on back order for long periods of time.
- 92 Patients do not know that they have a say in policy development. Most are so stressed when coming for evaluation, it may be difficult to explain the process, but UNOS should have an easy to read (8th grade level) section that explains policy development and how the patient can take part.
- 93 Some of the above I did not know about so I will be using these tools in the future.
- 94 Staff member that are in management may not directly work with patients. It seems that the best coverage and utilization of knowledge would be to send representatives that actually are involved in the transplant setup from listing, transplant, and post-operative care.
- 95 That living donors receive priority on the transplant list - this is crucial information and particularly for those who donated prior to the extra points policy going into effect.
- 96 The importance of following up with the transplant center or licensed professional after donation for a live donor.
- 97 The inventory levels of the online store has presented challenges throughout the year. There never seems to be enough to meet the need. Especially living donor and What Every Patient Needs To Know.
- 98 the system is hard to navigate
- 99 The UNOS information packets that are wonderful should be made available in Spanish-- you have all the books - just need to package with the letters.
- 100 The website needs to be simplified for persons from a nonmedical profession.
- 101 There could be some emphasis on the role of the HLA lab once in awhile, or a story on it.

- 102 There's a lot of information but I feel like it takes a while to locate it and/or navigate the databases.
- 103 They are met. I always refer my patients to review the UNOS website and I have no complaints so far.
- 104 Transplant Center level statistics regarding compliance on living donor follow up requirements, as well as break out detail on complications, morbidity and mortality.
- 105 Unknown
- 106 unknown
- 107 updated information about data on live donor risk and mortality
- 108 We need to have final UNOS guidelines to establish the evaluation , acceptance criteria and exclusion criteria for living donors with the intend to enforce those across all living donor programs is US.
- 109 We struggle for our non-English, non-Spanish-speaking patients to try and get them all educational materials translated.
- 110 When adding living donors to UNOS, I would like to see the UNOS ID and match ID be written in larger letters. They are difficult to see, and there is plenty of room on the screen.
- 111 would be nice to connect with other transplant social workers, also i have had a difficult time accessing information about transplant for children. the info I've found is for young children who are themselves going through transplant but not much for those whose parents or grandparents are undergoing transplant
- 112 Would like more education regarding Living donation for both recipient and potential donor.
- 113 Would like to have teaching materials in several languages for donors and recipients.
- 114 Would love to see "self survey" or "self audit" tools provided to transplant administrators to practice or self audit their center to improve compliance with living donor care, vessel storage and recipient compliance. Feel like this would allow programs to be more proactive in their compliance than react to the negative findings from an audit.
- 115 yes
- 116 yes
- 117 Yes, need some pediatric specific material
- 118 Yes, the web site is easier to find things than it was a couple of years ago
- 119 Yes. Stop informing me about the donor number and match run number during organ offer calls. I just want to press the button, go to the computer, and then go back to bed.

Regional Meetings

Question: What do you find most useful about the regional meetings?

- 1 1. Receiving update from UNOS leadership on strategies and goals for the upcoming year for UNOS
- 2 2. Receiving updates from Regional Reps on UNOS Committees
- 3 All aspects of the meetings
- 4 Any topic that is current : live donor exchange was the most recent I attended and it was very informative. However if you are sending staff from an organ specific program it's helpful to have the most applicable topics presented to make the meeting the most useful to clinical staff.
- 5 Being a part of the public comment process and hearing from other centers about how policy may or does affect them.
- 6 Being able to meet with the region
- 7 Bringing back pertinent information, packages of material, new/updated rules and regulations
- 8 brings back current issues
- 9 Can't answer because I've never attended a regional meeting
- 10 Chance to ask questions of committee members and the councillor.
- 11 chance to keep up to data on issues
- 12 Changes in policies that affect our institution.
- 13 Clinical updates, and the business meeting
- 14 Collaboration & sharing of ideas
- 15 collaboration and information sharing
- 16 explanation and intent of policy
- 17 Collaborative session and organ specific sessions
- 18 Collaborative sessions (day before meeting in Region V), organ-specific updates, UNOS update
- 19 Committee reports as well as UNOS speakers to discuss upcoming issues and answering questions
- 20 committee reports especially on voting items
- 21 committee reports, and opportunity to provide feedback on issues
- 22 Committee reports, OPO meetings (when they occur) and information shared
- 23 Committee reports; policy discussions; President presentations.
- 24 Committee updates - what's happening
- 25 Committee updates and discussion of public comment items
- 26 committee updates and UNOS priorities. Also networking opportunities
- 27 Committee updates
- 28 Explanations of proposals
- 29 committee updates, chance to network with other OPO/transplant center staff.
- 30 Committee updates, etc.
- 31 Committee updates, networking.
- 32 Connecting with others
- 33 Connecting with regional leaders in the field, access current info and policy development
- 34 current changes and on-going learning

- 32 Differences between other centers and ours and how they differ/same
- 33 Discussion
- 34 Discussion among centers
- 35 Discussion of items out for public comment
- 36 discussion of policy out for public comment/other center issues with policy
- 37 discussion of policy with regional members
- 38 Discussion of proposals and networking opportunity
- 39 Discussion of public comment proposals. Updates on UNOS statistics
- 40 discussion of topics in and out of meeting
- 41 discussion re new policies
- 42 Discussion re policy interpretation/management trends
- 43 Discussions about the many regulatory requirements.
- 44 Discussions among other regional members
- 45 Discussions of proposed policies
- 46 Discussions regarding upcoming policy changes or implementations
- 47 Do not get the opportunity to attend
- 48 Does not pertain to my job at this moment
- 49 Don't know. Never get reports
- 50 education day
education portion,
- 51 the spats between docs are entertaining (this is confidential right?)
- 52 Examples of how programs had a solution for common problem. Collaboration with others
- 53 Feedback on bylaws interpretation
- 54 Forums
- 55 General information sharing
General information. Sometimes for Administrators the discussions are too clinical, but
- 56 good to hear the conversations.
- 57 General sharing of information
General UNOS Operational Update with National Trends and review of issues.
- 58 Committee Updates
- 59 General update re; policy changes, what's going on, etc.
- 60 get an update on policy changes
- 61 get messages to the UNOS reps and the CMS people - and hope they hear it.
- 62 Gettin an overview about trends within the region. Networking.
- 63 getting the points of view of other transplant centers and OPO's regarding issues
- 64 Getting updated general ideas about what is going on and discussing about new policies.
Good forum for discussing, evaluating, and planning for changes. Helps institutions remain
- 65 compliance and permits members to influence policy direction.
Good opportunity to see what is going on in the various committees. I enjoy the committee
- 66 reports and the proposal discussions
- 67 great to keep up to date on what is happening, changes in the organization.
- 68 Great updates on policy and a good time to meet with other OPO staff.
- 69 handout summaries of proposed changes
- 70 Having a representative involved in policy discussions
- 71 Heads-up on potential policy changes.
Hear about policies we didn't know existed - also learn about new policies coming down the
- 72 pike.
- 73 Hearing about relevant issues concerning Tx
- 74 Hearing about the different organs and what the committees are doing

- Hearing from persons from several organizations who face the day-to-day challenges of implementing OPTN/UNOS regulations. People are very candid in the informal environments.
- 75
- 76 hearing the information shared by specialists represented in the room.
- 77 Helps me better understand the thoughts behind policy changes
HLA committee meets separately, then main meeting catches you up to what other committees are working on.
- 78
- 79 I am not the representative
I am not the representative from our center, so I do not attend the meetings and have no input.
- 80
- 81 I am the representative for my institution. I find the meetings informative about policy in general and I gain insight into issues in other organ areas as well as my own.
I appreciate real examples of what other centers have experienced. Networking is very helpful. I appreciate reviewing new policies and open forums to discuss how others have implemented the change.
- 82
- 83 I attended the most recent one and found the person from UNOS giving an update about what is going/coming etc. very useful.
- 84 I do not really hear anything about them from the attending staff members.
- 85 I don't attend. Not sure if someone else does
- 86 I dont know, I never go.
- 87 I have not attended for many years but plan to attend the next meeting.
I often learn new information or I am able to understand, in a bigger context, the information being considered at the national level.
- 88
- 89 I only attend the regional education forums which are usually excellent.
- 90 I personally have not attended.
- 91 I think the networking aspect is critically important.
I usually don't hear back about the meetings. Is there a summary online or a handout to give attendees so they could bring it back to dept so everyone is aware of what occurred at mtg?
- 92
- 93 Identification of beest practice and new strategies for development
- 94 information about upcoming policy changes
- 95 Information and Networking
- 96 Information and updates presented
- 97 information from committees on current issues
Information on Policy changes and proposal provided. Excellent opportunity to meet with other in the field and listen to presentations & discussion regarding policy.
- 98
- 99 information shared between programs. regulation information shared
- 100 Information sharing
- 101 Information sharing to bring back to the transplant center
Information sharing, opportunity to discuss proposals out for public comment and networking.
- 102
- 103 Interaction and discussion about upcoming policy revisions-specifically finding out how others in the region feel about the potential implications.
- 104 Interaction with other transplant professionals and discussion of policies in process
Keeping apprised of all the forthcoming policy changes.
- 105 Networking with my fellow regional OPO representatives.
- 106 learn about common issues across organs
- 107 learning about policies open for comment
Learning about the proposed changes to policy or hearing about the latest controversies is better in person than reading it online or in an email.
- 108
- 109 Meeting other representatives
- 110 most current information and hearing other neighboring programs views.

- 111 N/A
- 112 N/A
- 113 N/A
- 114 n/a
- 115 N/A - have not attended
- 116 NA
- 117 NA
- 118 Na
- 119 National overview. Public comment sessions, Networking with OPTN/UNOS staff and other centers, labs and OPO
National unos updates

Committee updates
- 120 Discussion of policies in development
- 121 national updates from committees, networking in our region
- 122 Net working
- 123 network with other transplant professionals
- 124 Networking
- 125 networking
- 126 networking
- 127 networking
- 128 networking
- 129 Networking
- 130 networking
- 131 networking & updated info of committees presented
- 132 Networking and committee reports.
- 133 Networking and discussion of regional challenges
- 134 Networking and organ specific breakouts
- 135 Networking and the UNOS update by a UNOS representative or officer
- 136 networking and updates on policy information/changes
- 137 networking for best practices
- 138 Networking opportunities
- 139 Networking opportunities. Ability to discuss potential changes.
- 140 networking with colleagues and discussions on topics
- 141 Networking with colleagues in the industry; Learning from other colleagues.
- 142 networking with other centers
- 143 Networking with other Transplant Professionals
- 144 Networking with other Transplant Professionals
- 145 Networking with peers, getting updates from our opo and unos.
Networking
- 146 Review of upcoming UNOS activities and proposed policies
Networking
- 147 SRTR
- 148 Networking, clinical forum
- 149 Networking, committee updates
- 150 networking, discussions
- 151 Networking, opportunity to have input into policy development

- 152 never attended UNOS meetings
- 153 New information, updates about the transplant practice.
- 154 new policies
- 155 New policy discussions and coming to regional opinion.
- 156 new policy info
- 157 new tools, updates, resolutions to UNET situations in collaboration with our systems, etc.
- 158 News and policy updates
- 159 no idea, no feedback comes to my level from the person(s) who attend
- 160 Open discussion about proposals
- 161 Open discussion.
- 162 Opportunity to connect with regional partners.
- 163 Opportunity to dialogue with colleagues
- 164 opportunity to provide some feedback and vote on some policies, though not all
Opportunity to remain current with policy changes, networking with other transplant
- 165 professionals
organ specific policy changes and discussions. networking with professionals from other
- 166 areas of the region.
- 167 Our representative did not share with us the information.
Our Surgeons attend MAPB meetings. I am not sure of what information they bring back to
- 168 the rest of the professional staff.
Our transplant nephrologist (UNOS rep) attends and enjoys updates, networking,
- 169 discussion, although he doesn't always share information.
Overview of public comment proposals. Additional information about complying with new
- 170 policies that come out.
- 171 paired exchange policy updates
- 172 Participation in the process
- 173 participation, being heard, networking, lobbying
- 174 peer to peer interaction and policy discussions
Personally, never attended. Those attended usually don't talk much about their experiences
- 175 at the meeting
- 176 Placing a face behind the voice/email.
- 177 policy discussion
- 178 Policy discussion and networking
Policy discussion, proposed changes, networking within the region and across with other
- 179 region (recently Region 3 and !! met together) and I enjoyed it very much.
- 180 Policy discussion, voice in process
- 181 Policy discussions
- 182 Policy discussions
- 183 Policy discussions - networking
- 184 Policy reviews
- 185 Policy updates
- 186 policy updates
- 187 policy updates
- 188 policy updates
- 189 Policy updates and discussions and the chance to see and Ali to other members.
- 190 policy updates and impending changes; committee activity reports
Policy Updates
- 191 Face to face meetings with colleagues
Policy updates
- 192

- Networking
- 193 Policy/future policy updates
 - 194 Potential policy changes related to Kidneys.
 - 195 Powerpoints and discussions in the business meetings; networking.
 - 196 Presentations from committee leaders
 - 197 Presentations re: OPO performance for our region
 - 198 proposal discussion
 - 199 Proposals, policy updates
 - 200 Proposed policy changes are reviewed, Committee Updates
 - 201 Quick updates
 - 202 Receiving info about current news in transplantation and networking with other transplant programs
 - 203 REgional and national policy updates
 - 204 regional committee updates, national updates
Regional representation and networking opportunities.
 - 205 Collaborative meeting the day prior to the business meeting.
 - 206 Representative attend; I do not attend
 - 207 Representative goes
 - 208 Review of the proposals.
 - 209 Review proposals
 - 210 Seeing and meeting the other transplant individuals from the region.
Seeing colleagues, hearing policy descriptions. Mostly, they are very dry and the reports just read the UNOS staff's slides. Often, the slides are in UNOS-speak and difficult to really understand.
 - 211 Shared information from all disciplines
 - 212 sharing information, educational component
 - 213 sharing of information and practices
 - 214 Stay current with our region and the presentations etc.
Staying up to data on liver, heart and lung practices and policies as we don't have transplant programs in our service area.
 - 215 Talking to the other people about their experiences. Hearing what is happening at our transplant centers in the region.
 - 216 Talking with staff from other centers, ie networking
The collaboration between professionals at different centers and the chance to communicate offline with the OPOs.
 - 217 The collaboration of all aspects of donation & transplant that generates so much discussion on every aspect. I find interesting the passion and "stubbornness" that can be displayed often from transplant surgeons on behalf of their recipients and what the surgeons feel is "the only way to do things". It often generates very lively discussions that can result in great ideas for moving forward.
 - 218 The discussion relative to policy changes that are up for board approval
 - 219 The discussion surrounding proposed new policies.
 - 220 The educational offerings.
 - 221 the general thoughts about what is happening in the region and the country
 - 222 the information discussed and presented there; the networking
 - 223 The interaction between members and updates on policies.
 - 224 The knowledgeable discussions about policy proposals and the UNOS updates
 - 225 The most useful part of the meetings is talking about new issues in transplantations.
 - 226 The opportunity to air the unique needs created by our location.
 - 227 The opportunity to meet with peers face to face.
 - 228
 - 229
 - 230

- 231 the organ specific break out sessions
- 232 The organ specific updates
- 233 The overall updates by UNOS senior management.
The representative does not share information from the Regional meetings with transplant staff
- 234 staff
- 235 The UNOS general update about BOD plans/actions
- 236 The updates on UNOS activities and the policy discussions
- 237 tying into Regional collaborative meet and sharing best practices and networking
- 238 updates on policy
- 239 Understanding the positions UNOS takes on issues and activities of the UNOS committees
- 240 unknown
- 241 UNOS by law updates
- 242 UNOS staff presentations
- 243 UNOS update; discussions that give other perspectives.
- 244 Unsure if a representative attends.
- 245 upcoming policy proposals
- 246 Update and discussion of policies.
- 247 update and discussions with transplant colleagues
- 248 Update on current issues
- 249 Update on current policies and discussion of current proposals.
- 250 Update on current UNOS initiatives. Discussion with other centers
- 251 update on regional data
- 252 updates
- 253 updates
- 254 Updates
- 255 updates / current information / upcoming issue / policy change / networking
- 256 Updates and networking with regional transplant staff and UNOS representative.
- 257 Updates and the opportunity to comment on UNOS policy issues.
- 258 Updates from committees, policy updates
Updates from the UNOS committees on policy and by-law changes, the interaction with my Region and my UNOS Rep, the opportunity to speak freely and give input on organ and tissue donation in my state, region and for the future of the U.S.
- 259
- 260 Updates from the various committees
Updates from UNOS leadership and committees
- 261 Chance to meet those from other centers
- 262 Updates on bi-laws and changes in policies.
- 263 updates on information
- 264 Updates on new or proposed policies
- 265 Updates on new policies, chance to verbalize concerns/issues regarding DonorNet
- 266 updates on policy changes and committee activities
- 267 updates on UNOS changes and pro & cons to proposed by-laws
- 268 Updates on what is to come in the transplant world
updates regarding current happenings; committee updates; policy updates and proposed changes; networking with regional colleagues.
- 269
- 270 Updates, collaboration, networking
- 271 Very little
- 272 Very little, other than voting on specific policy issues.
- 273 Voting on current issues before the transplant community
- 274 We always send representative(s) to the regional business meeting; we have regional

education primarily by webinars due to travel, cost, staffing, etc, so it has been helpful to get more staff exposed to information

275 We rarely get feedback from the meetings

276 whole thing

277 Will attend my first at the end of this year.

278 Wish we could attend-

279 Yes

280 yes

281 yes

Regional Meetings—Suggestions

Question: What are your suggestions for improving regional meetings?

Number	Response Text
1	.
2	?
3	A few more updates on the DDC and registry progress along with the Paired Exchange program progress
4	ability to do live web if we cannot travel
5	Ability to get followup from UNOS on issues raised at these regional meetings.
6	Afternoon session tends to lose attendees therefore I would recommend a working lunch with networking at the end of the meeting.
7	Allow for more non physician participation. Many times only physicians are acknowledged in the meetings and others ignored
8	allow live meeting or conf call-have meetings near airports
9	Allow many personnel to attend from host center
10	An introductory activity so you get to meet and greet so you know who is attending and from where. Also required attendance for all transplant centers.
11	appreciate the current format/agendas
12	Back in the day, I enjoy the all day seminars.
13	Betsy Region 2 does a great job with a feisty audience!
14	better food
15	Better meeting facility, more time for discussion
16	better representation at the meetings
17	Breakaway sections to discuss your organ speciality
18	Broaden the topics. The meetings are very specific and have a narrow focus.
19	Can't answer because I've never attended a regional meeting
20	CEPTC / education component tied into it.
21	changes times of year-go back to March/October- it is really hard to travel in December
22	Committee presentations often could be condensed more effectively.
23	continue to rotate locations across the region
24	Continue with the educational offerings the day before the business meeting. Develop the collaborative meeting prior to the business meeting. These might benefit from a stronger focus on policy and regulatory requirements and process improvement. The material seems to be 'recycled' a lot and becomes less engaging. There needs to be a balance between these current 'best practice' presentations and more traditional business improvement strategy. How about engaging the region prior to the meeting to see what
25	THEY want to see/learn about?
26	Do it online through an internet meeting protocol.
27	Do more by live meeting. Travel time is wasted time.
28	Does not pertain to my job at this moment.
29	Don't combine 3 & 11 again.

- 30 find ways to improve attendance.
- 31 focus on quality
- 32 Geographically difficult to get to
- 33 Have a limited open forum period to discuss current regional issues/concerns
Have proposed policy changes written in English. Written by someone who writes using the
- 34 English language as opposed to lawyer or government jargon.
- 35 Having the President there is excellent and sends a strong message of support.
host a 30-45 minute best practice presentation - highlighting a OPO and a TX Center unique
- 36 approach to anything....more to stimulate best practice conversations and share ideas
- 37 I am not the representative
I attending the transplant forum held in Richmond for the transplant centers. Is there
anyway to do the same thing for the OPO's? I would be happy to volunteer to help as would
- 38 many others.
- 39 I cannot identify a need at this point
- 40 i could care less about the OPTN business etc. We are there to discuss policies and vote
I don't have any new suggestions, I think Shannon Edwards does a great job setting them up
- 41 and organizing things
- 42 I don't have any special requests at this time.
- 43 I dont know
- 44 I have no suggestions. I like them as they are.
- 45 I haven't personally attended the meeting.
I liked it when the educational forums were presented twice a year, which is no longer the
- 46 case. It was a good way to network and to obtain CEPTCs.
I liked the old 2 day regional meetings where the first day was an educational component
and the 2nd day was the business meeting. Offer MD and RN CEUs and CEPTCs.
- 47 I think our meeting run pretty well
I think our region 4 meetings are handled well. Sometimes the committee reports at the end
- 49 are a bit rushed, but I can't think of a way around that.
I think that the meetings are very well organized and scheduled appropriately so as to allow
travel in a single day.
- 50 I usually don't hear back about the meetings. Is there a summary online or a handout to give
attendees so they could bring it back to dept to distribute so everyone is aware of what
- 51 occurred at mtg?
I would like to see the meeting more balanced by representing topics on both transplantation
- 52 and donation.
I would recommend a meet and greet - something formal so newcomers can feel welcome
- 53 and get to know transplant staff from other centers.
It is always held on the same place. It will be helpful to rotate in the cities of member
- 54 institutions
It is mostly geared towards the OPO's, a little more information regarding transplantation
- 55 would be nice.
- 56 It would be helpful if it were possible to fly in and out on the same day.
- 57 Keep rotating the location
- 58 Keep topics and discussions focused: continue associated educational opportunities
- 59 Keeping them on time
Keeping to agenda, updating issues on all organs (not just single organ dominance of any
- 60 meeting)
- 61 Keynote speaker on a transplant topic....CME, CEU maybe the night before or at lunch
- 62 Less Paper, more digital.

- 63 Less redundancy. More Dynamic presentations. I can read the powerpoint myself. Most presenters read verbatim what the slides say. Yawn.
Limit the amount of time for each committee representative to present materials - stay on point
- 64
- 65 Live meetings so that more can attend by teleconference and web link.
- 66 Make physicians act like adults. Sorry. Just the way I see it.
- 67 make region 3 smaller
- 68 Make sure slide sets get sent out after the meeting. Timely distribution of the minutes
- 69 Make sure they are easy to travel to, and keep the agenda focused.
- 70 make them more accessible to more staff
Make travel worthwhile. Would try to add an educational component, or have committee members give more detailed background on committee thoughts and actions.
- 71 Maybe adding one break out session. This allows regional topics to be addressed without it having to be at a national conference. For instance, we'd be happy to talk about air/ground transportation best practices - and there may be 15-20 people that want to hear that, but would not be able to at a national conference.
- 72
- 73 more educational opportunities
- 74 More informed staff available for public comment items.
- 75 More meetings with Regions 3 and 11 combined as was their history.
- 76 More opportunities to discuss regional issues
- 77 more regional initiatives
- 78 Move through the information more quickly.
- 79 N/A
- 80 n/a
- 81 N/A
- 82 n/a
- 83 n/a
- 84 N/A - have not attended
- 85 NA
- 86 NA
- 87 NA
- 88 NA
need the ability to have better teleconferencing for members that can not attend due to financial or on call responsibilities.
- 89 Need to be sure there are enough materials. At the most recent meeting I attended, there were several attendees who did not get the meeting materials.
- 90
- 91 needs to be more time for dialogue and not just presentations
- 92 No
- 93 no
- 94 No concrete suggestions, meetings seem fine.
- 95 No opinion
- 96 No problems
- 97 No recommendations.
- 98 no suggestions, satisfied with time frame and meeting content.
- 99 none

- 100 None
- 101 none
- 102 none
- 103 none
- 104 None
- 105 None
- 106 None
- 107 None
- 108 None
- 109 None - UNOS does a good job of condensing a lot of information into a small chunk of time. Also appreciate the 2 meetings face-to-face and 2 meetings using technology. Best use of time without losing the value of face-to-face interaction.
- 110 none at this time
- 111 None at this time.
- 112 None at this time.
- 113 None at this time.
- 114 None.
- 115 none.
- 116 none-good meeting
- 117 Not at this time.
- 118 Not sure they are really long, wish everyone came prepared to participate
- 119 Never have attended- unable to provide any feedback
- 120 Our location in Region 10 is not desirable but it is what the members wanted.
- 121 Our regional meetings run very well - no suggestions at this time.
Personalize slides to Region, or have the person reporting out have a better understanding of the slides.
- 122 of the slides.
- 123 Please have a meeting in Washington, DC
prefer face to face meetings rather than conference calls since in person meetings generate more discussion and dialogue
- 124 more discussion and dialogue
- 125 pretty good as they are
Provide policy review first to allow ample time if needed and some informational presentations at the end
- 126 presentations at the end
Provide some financial support so more organizations may attend. Too many member organizations see attendance at UNOS meetings as the first budget item to cut.
- 127 Provide the opportunity for more people on the "front lines" who actually work on allocation and with the recipients to attend the meetings. I realize this is mostly up to the OPOs; however, I don't believe it is conveyed to the general OPO staff that they may attend the meetings as a public forum.
- 128 meetings as a public forum.
- 129 Region 4 is run well...no complaints.
- 130 Representative goes
- 131 rotate location
- 132 Rotate meetings to different sites again
- 133 Rotating meeting sites if possible
- 134 rotating the venue to allow better proximity periodically might help
- 135 See above.

- seems to always be on a friday which may be good for amny but amybe sometimes on a
136 monday
- 137 Sharing more information on Best Practices and methods to increase utilization
- 138 shorter
- 139 shorter
skip some of the unimportant committee updates, or figure out a way to limit them to a
prescribed timeframe. Listening to someone blather for >10 minutes about the multicultural
140 affairs committee is not a good use of anyone's time.
Some of the policy info is boring and time consuming-- maybe have a teleconference for
141 this-- so more could attend.
- 142 stay focused
the chair of specific committees should participate by phone when important policies are up
143 for voting.
- 144 The meetings are pretty dry. Could one get CEUs for it?
- 145 The pre meeting dinner was an excellent idea!
the recent merge of regions 3 and 11 was very good as there was good discussion on how
146 proposed changes in pact the regions
There could be more data about how our region compares with others / suggestions from
other regions about how to improve our performance. We should hear more about waitlist
147 trends; discard rates (kidneys), deaths waiting for transplant
There must be a way to mandate that all attendees stay to the end of the meeting. One
suggestion would be to put the organ specific committee reports at the end of the agenda
148 with Kidney/Pancreas last.
they have significantly improved over the past years and I found the last meeting very
149 informative on ethics
- 150 unknown
- 151 unknown
- 152 unknown
- 153 Unsure if a representative attends.
Use the full day. We are often rushing through important topics so that people can fly out in
154 the late afternoon.
Use the regional meetings for a standard ongoing training about UNOS policy and
regulation. Each transplant hospital is required to maintain staff competency and continuing
education. It would be helpful if UNOS facilitated a more easily accessible training program
staff could attend or participate by webcast to maintain ongoing competency regarding
155 UNOS / OPTN regulation.
- 156 Utilize webmeetings to conduct regional meetings to keep cost down.
- 157 Vary location and day of week.
- 158 Videoconference
- 159 Webcasting
- 160 When offered as webcate or there is listening opportunities we try to be involved
- 161 Will attend my first at the end of this year.

Evaluation Plan—Usefulness

Question: What do you find most useful about the evaluation plan?

Number	Response Text
1	The extent of the information
2	Resource for how to remain in compliance.
3	Thoroughness.
4	The hyperlinks are beneficial for supplemental and supporting information. the ease of finding information and the way that it is set up to distinguish OPO from TX
5	Centers
6	N/A
7	easy to follow and understand
8	outlines exactly what needs to be done to meet the requirement in a concise wayl.
9	Keep up with regulatory changes
10	Interpretation of guidelines, what surveyors are looking for.
11	comparing expected rates vs transplantation rates I had to pull it up to refresh myself on it. I have not looked at it in some time. I tend to access policies and bylaws when I need questions answered. However, I review changes when sent, but to be honest don't remember receiving 2011 updates.
12	Update
13	Update
14	n/a
15	Well organized, easy to use, accessible and current
16	very specific description of how to comply. Love that is separates how the policy applies to the differencnt estates (OPO, vs Transplant);
17	Very useful guide. I reference it all the time.
18	N/A
19	Everything that you need to know to run a transplant program.
20	current updates that link to policies
21	Changes highlighted in blue. Very helpful to understand up front the expectations for participation so that we can align our practice consistent with good patient care and compliance
22	Clarity of the rules
23	Clarity of the rules
24	Good guidance for demonstrating compliance with policy.
25	Allows updating of policies to maintain compliance. I really liked the "Overview of Policy Modifications/Board Actions and Affected Professionals
26	summarization that used to be sent out right before the evaluation plan.
27	Good reference
28	Great reference when needed
29	the changes are highlighted The policy pages that delineate whether the policy applies to the OPO, HLA lab or Transplant
30	Center
31	How we will be evaluated and the specifics
32	Areas relating to OPOs.
33	understanding how auditors will be evaluting compliance issues.
34	I do not use it personaly our manager does

35 It is important to know exactly what the transplant center is responsible for
36 update section from last plan publication date
37 Compliance monitoring
38 I appreciate the policies each give suggestions on how to be in compliance. This has been helpful.
39 SUMMARY CHANGES AND LINKS TO THE POLICIES
40 Reviewing the information to determine if we are meeting requirements.
41 the information about what is needed to comply
42 Used as reference for some standards
43 As a QA Director of an OPO, it serves as a guide to me for ensuring our staff understands the specific expectations of UNOS for members to remain in compliance; it helps me identify when we are out of compliance.
44 Way too long and hard to follow.
45 The changes are highlighted in blue, hyperlinks are provided.
46 I read the evaluation plan
47 I like that it's online.
48 self explanatory...we have a plan
49 Reading it after doing this survey
50 Help with maintaining compliance with regulations
51 it helps guide policies/QAPI
52 the detail and explanation
53 That we have one.
54 Nothing useful.
55 Compliance
56 The summary of policies and updates
57 changes to the policies and how to be compliant with these
58 Easy to find needed information
59 red highlighted changes and 1 page overview of how to comply
60 Keeps our performance expectations in the forefront of our minds.
61 Guidelines for allocation
62 assist with QAPI
63 Summarizes key requirements
64 I have looked at it, but haven't done much more than that.
65 The plan is fairly straightforward to follow allows for a uniform policy with which to follow.
66 The description of how to comply
67 Links to actual policies.
68 ability to search the document electronically
69 it keeps me up to date with current policy and regulatory "best practice"
70 Validating understanding of requirements.
71 Help us keep our processes compliant with CMS/UNOS requirements.
72 Guidelines for compliance with OPTN policies
73 All updates- Would like more input on how to search the data- Not too familiar
74 having access
75 NA
76 Its comprehensive nature.
77 Policy guidelines
78 formulating changes to policy or practice to be in sync with OPTN in a timely fashion
79 helps operationalize most policies.
80 information on the most common areas of non-compliance
81 searchable - thank GOD!

- 82 didn't know about it
- 83 provides overall easy to use summary
- 84 The information provided on exactly how to comply with policy
- 85 Provides detailed info regarding policy implementation
- 86 Every aspect of it
- 87 It provides some insight & guidance
- 88 Survey preparation/internal policy review
- 89 Help us understand what we need to focus on
- 90 Answers the day to day questions that arise regarding waitlist management
Our center uses this plan to make sure we are following policy and it helps when prepping for
- 91 audits.
- 92 Refer to it frequently for updates and for guidance.
- 93 It is simpler to read/ navigate than the policies & bylaws
- 94 The section for each policy that tells us how to compliance will be measured.
- 95 Overall mimics the guidelines we use as an OPO.
- 96 Knowing where the emphasis is in our community or professionals.
- 97 being able to reference rules and expectations
- 98 Again - really does not apply to me as I am a living donor.
Updated policies and implications for transplant center practice. Unfortunately, do not
- 99 reference often enough and get behind.
- 100 format
- 101 Good place to go for updates, like that they are highlighted
- 102 No opinion
- 103 hihlighted changes
- 104 Everything
- 105 Supplement to UNOS policies
- 106 clear expectations
- 107 Helps interpret vague OPTN policy language
- 108 Updated Information
- 109 Explains the process for policy development and implementation
Format and comprehensive nature of it. It is applicable and helps to clarify questions
- 110 regarding UNOS expectations.
- 111 More in depth means necessary to maintain compliance.
- 112 It helps with internal policy and protocol development.
- 113 helps with compliance
- 114 expanded explanations
It outlines each policy clearly and the member responsibilities as well as how DEQ will
- 115 assess for compliance
- 116 It tells you exactly what to expect from an audit and how to comply with policies
- 117 All of it.
Summary each quarter of policy changes.
- 118 Sections 4 and 5 of each policy.
- 119 Highlighted changes and links to bylaws and policies
- 120 Policy Updates
- 121 Good
- 122 good guideline
- 123 Identified changes
- 124 Easy to read - quick 1 to 2 page guides
- 125 Being able to access it on-line

126 Clearly noted updates each quarter.
127 how compliance is monitored, how our program is measured and results
128 I only get told what we need to do to meet requirements. Someone else is responsible for
129 passing along the content of the document.
130 being able to search
131 How compliance will be measured
132 Explanation about how compliance is measured
133 it details how specific components will be evaluated
134 What specifically is being evaluated.
135 It is a document that we can refer when we have questions.
136 new updates are highlighted
137 confirming that we are in compliance
138 This was a recent introduction and I find it very helpful in trying to insure compliance with all
139 the necessary requirements my different departments in our facility
140 The plan is clear and concise the fact that items are highlighted is a plus.
141 They provide a framework for day-to-day transplant center operations and UNOS site survey
142 preparation
143 The explanation of how to comply is straight to the point allowing centers to conform while
144 maintaining a flow to patient care and not causing disruption to a center unlike Medicare.
145 organized way of checking
146 policy changes highlighted in blue
147 To double check that we are doing the appropriate things
148 Knowing key items to address...good summary.
149 .
150 protocols,
151 n/a
152 Very specific in terms of what surveyors look for as evidence of policy compliance
153 actionable item

Evaluation Plan—Suggestions for Improvement

Question: What are your suggestions for improving the Evaluation Plan?

Number	Response Text
1	.
2	A summary of what is new each quarter, and maybe these exist because my quality department does pull it for me.
3	Assists in revision of policyies and procedures. At times the language is vague and lacks authoritative position - which is frustrating for
4	Transplant Centers. We will follow the rules - we just need clarity about what those rules are.
5	Better table of contents with specific policy on specific page of document. Change the layout of the evaluation plan so that it can be used as an audit tool. currently the plan has to be converted. Make it in a format that would allow for policies and bylaws to be
6	sorted by member type for ease of finding. Create two evaluation plans, one for OPOs and the other for Transplant Centers, a document of three hundred and something pages is a little rediculous. Another suggestion may be to split it by policy or bylaw section and subsection so centers/OPOs may print what is
7	applicable to them.
8	Define evaluation
9	dileneating the changes more clearly and as a total unit, so you don't have to go to other places to review what the changes are.
10	Do not use it.
11	Freda Wilkinson put out a "quick tip/guide" for patient notification letters (great!!!). I think more "quick/tip guides" as well as some best practice examples would be VERY helpful. I am embarrassed to say although very involved with national policy I really only very recently started using the evaluation plan. Think we are all so focused on CMS final rule and the interpretive guidelines it gets hard to keep reviewing other regulatory references and you end
12	up dwelling on the CMS ones. I am on the pre-side primarily, but think this is good info all coordinators need to know.
13	perhaps presenting a webinar as to usefulness from a nurse perspective would be helpful
14	I don't personally use it but my Qualty and Safety officier does
15	I like it just as it is
16	I think it works very well. The instances of non-compliance that I'm aware of have not been because of lack of clarity in the evaluation plan
17	I think the name is confusing. Now that I know what it means I utilize it. I'd like a similar document that is comprehensive of all policies & bylaws. Perhaps the
18	'rewrite' project will accomplish this.
19	If possible and needs to be shorter. We are regulated to death.
20	Improved table of contents/index to search for items quickly
21	Is there a way to condense it? It is hugely long and not easy to find information. I would like an easier way to identify
22	revisions, updates, or clarifications
23	It is too long, but not sure how to fix that. Its a very large document - put links within the document that can take you from the table of
24	contents to the specific policy section you are interested in.
25	It's so large, that it is difficult to navigate Just looking at it now? 398 pages? How could this possilbly be necessary? What are the
26	key points?
27	Large plan - sometimes difficult to find information
28	Lengthy. Needs to be bulleted so that it can be more easily read/skimmed.

- 29 Links do not always match up to where you need to go.
- 30 make date effective more clear
- 31 make is accessible to download as a "write" document
- 32 Make it easier to find policy
- 33 make it more user friendly
- 34 Make it part of the general training of new members and also make sure all centers are training staff on the availability of these tools
- 35 Make it readable - less than one page. Again, get someone to write it in concise English. Currently it is not readable by normal human beings. Once it is put into concise English and made readable there could be actual suggestions for improvement.
- 36 Make it shorter
- 37 Many minds greater than mine are working on this.
- 38 Mke an electronic compliance tracking checklist
- 39 More direct and specific
- 40 More usable index
- 41 N/A
- 42 n/a
- 43 N/A
- 44 N/A
- 45 n/a
- 46 NA
- 47 NA
- 48 NA
- 49 Needs to be easier to read. Need a better process to highlight changes.
- 50 No suggestions
- 51 None
- 52 none
- 53 None
- 54 none
- 55 none
- 56 none
- 57 none
- 58 None
- 59 None at this time
- 60 None at this time.
- 61 None at this time.
- 62 none for now
- 63 None.
- 64 Not sure
- 65 organization- difficult to find things. Have to refer to multiple policies to get all the answers.
- 66 Overall, it's hard to find what I'm looking for.
- 67 perhaps a summarized version
- 68 Plain english & brevity - not necessarily a "9-9-9" plan, but a damn decent effort at it would help. (I know I'm talking to the wind...)
Please, please consider drafting a template for centers to follow so that common areas for non-compliance (ABO verification) could meet both UNOS and CMS. We have been audited recently and even with a change in either UNOS or CMS policy, things that were acceptable at one audit are now no longer acceptable. This would make things so much easier for centers to be compliant rather than guessing and expending an inordinant amount of effort trying to do things correctly only to find we are not.
- 69

- 70 seems that opo and transplnt are mixed together , seperating them would be helpful
- 71 shorten
- 72 Simplify it - streamline it, it's too large. Improve table of contents or searching for a specific topic.
- 73 Some of the wording is not as stated in the policy.
- 74 Sometimes confusing what is under revision and what is current
- 75 Standardized forms, such as ABO verification prior to surgery, would be GREAT.
- 76 Streamline the document
- 77 The plan needs to match what all regulatory people require of transplant programs. There needs to be a "table of contents" or something that allows you to quickly find the section you are looking for and skip to it. I find the current format difficult to navigate
- 78 To soon for me to make any recommendations-
- 79 Too large. I would just like to see policies that pertain to transplant centers and I would like them grouped by categories that are easy to navigate. I feel like we're always discovering policies that we never knew existed.
- 80
- 81 Too large...wish it were a bit more user friendly.
- 82 UNOS and CMS should use the same tools to ease the tremendous burden on centers

UNOS Website-Usefulness

Question: What do you find most useful about the redesigned UNOS website?

Number	Response Text
1	Access to data/statistics
2	Access to our listed population lists
3	Accessibility of organ offers and ABO verification
4	actually, I use it much less often because a lot of what I need was moved.
5	ah that explains it...
6	all of it
7	As useful as the previous one
8	automatic transfer
9	Best practice articles are hard to find!!
10	Better designation of UNOS role to the OPTN
11	Better organized than before.
12	central location
13	centralization
14	clarity has improved
15	Clear and happy vibrant colors.
16	Clear delineation of areas of responsibility
17	data
18	data , policies and bylaws
19	data reports
20	data reports
21	Data resources
22	data retrieval
23	Didn't really have much effect on my pracitce.
24	donor net
25	dont usw
26	don't know
27	Don't like the redesign at all. Much easier to use when both UNOS and OPTN content were in the same place.
28	don't use it
29	dropdown menu of frequently used pages
30	Ease of finding where to go on the site.
31	Ease of navigation
32	Ease of use
33	Ease of use
34	ease of use
35	Easier access to updated information
36	Easier to find data.
37	Easier to find information
38	Easier to navigate
39	easier to navigate to where I want to go to find the information I desire
40	Easier to navigate, clear, resources easy to find
41	Easier to navigate. Good links.

- 42 Easier to read
- 43 Easier to read and find the information you need.
- 44 Easier to see what you are looking for
- 45 easier to track down data
- 46 Easy access to direct support.
- 47 easy link to the OPTN website to access policies
- 48 Easy to find data quickly.
- 49 Easy to find what I'm looking for.
- 50 easy to navigate
- 51 easy to navigate
- 52 easy to navigate
- 53 easy to navigate
- 54 Easy to navigate
- 55 easy to navigate
- 56 Easy to navigate and data access.
- 57 Easy to navigate and find what is needed.
- 58 Easy to navigate where you want to go
- 59 Easy to navigate.
- 60 Easy to navigate.
- 61 Easy to use
- 62 Easy to use
- 63 easy to use
- 64 Easy to use-
- 65 easy to use and find information
- 66 easy to use, able to jump directly to what I need rather quickly
- 67 Easy to use.
- 68 Excellent resources to patients and public
- 69 fairly easy to navigate
- 70 Format is much clearer
- 71 getting quick statistics
- 72 Gives access to various information.
- 73 Hadn't noticed.
- 74 Have all necessary info in one site
- 75 Haven't noticed the redesign.
- 76 haven't used it enough to know
- 77 I can find what I am looking for in a very rapid manner.
- 78 I can get right to the data I need faster
- 79 I did not use the site before 2011.
- 80 I did not use this site before the redesign
- 81 I didn't realize it had changed.
- 82 I do like that for customers (patients all the policy information is taken off the UNOS website)
- 83 I don't have a hard time finding anything
- 84 I don't spend that much time to assess this.
- 85 I don't use the public one often so I have to search for things
- 86 I find the website to be more cumbersome now as it is laid out than previously.
- 87 I had some trouble navigating the new site but I'm getting used to it.
I have always found this confusing and it was not well explained to me when I started in this industry years ago by my OPO; the separation that the re-design brought about was helpful, especially for newer industry folks, to connect the dots.
- 88

- 89 I have not recently use the web site.
- 90 I haven't really used this site.
I like the links to the OPTN website so I don't have to figure out where to go next for
- 91 information I seek.
- 92 I like the policy/bylaws moved to OPTN contractor section
- 93 I liked it better the other way. It was easier to get all the info at one site.
I love the transplant trends section. It puts into perspective how many people are really waiting for an organ and it is a powerful tool to aid in educating the public about becoming an organ donor.
- 94
- 95 I sometimes find it difficult to find things. For the most part I like it.
- 96 I still cant find a darn thing!
- 97 I thionk it is more users friendly and easy to surf
- 98 it finally has a google search tool
It has taken me almost this whole time to realize I have to go to OPTN to find data.
- 99 Remembering the "unos.org" URL was much easier.
- 100 It is easier to locate information
- 101 it is easier to navigate
- 102 It is easier to navigate and more appealing visually
- 103 It is easy to navigate
- 104 It is more streamlined and easier to find items I am looking for.
- 105 It is ver easy to find what you are looking for
- 106 it is very easy to use
It was very difficult to access the OPTN site due to it's name. While the separation was essential for coporate structure, it made it difficult for those of us who accessed UNOS policies for daily allocation to find the policies. It took a lot more clicks and searches to find what we needed. The OPTN site is/was not very user friendly in contrast to the prior UNOS site which was very user friendly. Also, the
- 107
- 108 It works. I use it mostly for data and policy review
- 109 It's pretty, but I have such a hard time finding things.
- 110 Less clutter
- 111 less cluttered
- 112 less confusing about what is where and if you have the correct site for information
- 113 like the old one better
- 114 links and available information
- 115 Love the quick links (I am looking for...)
- 116 Makes the separation of duties & responsibilities easier to understand
- 117 More category tabs that help get to where you want more easily.
- 118 More easier and faster to complete
- 119 More easily able to navigate to what I seek
More streamlined, user friendly.
- 120 Links to OPTN Web site
- 121 More user friendly
- 122 More user friendly
- 123 more user friendly
- 124 Mostly to get current transplant demographic data
- 125 much simple to read
- 126 n/a
- 127 NA
- 128 NA
- 129 Navigation

- 130 neater
- 131 No comment to add.
- 132 No comments.
- 133 no different
- 134 No increases time of looking at information
- 135 No opinion
- 136 No problem finding what I am looking for
- 137 None
- 138 None, it takes extra steps to get to the policies
- 139 Not hard to find information that I am seeking.
- 140 Not much
- 141 not much
- 142 Not much.
- 143 not very useful when trying to find clinical information. Mostly public education now.
- 144 nothing
- 145 nothing
- 146 nothing
- 147 NOthing
- 148 Nothing
- 149 Nothing particular stands out from my point of view
- 150 Nothing. The change is confusing and the transfered data does not appear to be current.
- 151 Old habits die hard - I usually get to where I need to go but not always in the easiest manner
- 152 policy and bylaw dropdown
- 153 policies, Statistics, PowerPoint Graphs and graphics
Quick finding statistics to share w/my patients.
- 154 Information for patients regarding paired donation program
- 155 Quick like drop down box.
- 156
- 157 Separation of OPTN Policies and UNOS Bylaws.
Sorry but liked the original website better. Feels as if leaving UNOS and going to government now.
- 158
- 159 Stats are right up front on the main page
Still go to the UNOS website (as had been my custom) but am often redirected to the OPTN site which is where the info I need to find the most is located.
- 160
- 161 Access
- 161 The "I am looking for" search box
- 163 The ability to create a work order.
The 'I am looking for' option at the top of the page helps me what I need relatively quickly.
- 164
- 165 The link to the OPTN website for data reports. Although having to be redirected is not convenient.
- 166 The quick reference to data/statistics
- 167 There are a lot of categories to choose from
- 168 This was a terrible redesign.
- 169 too many clicks to take you from the main unos page to the policy and bylaw page.
- 170 Transplant Trends - the counter on the front page of how many are waiting, metrics, etc.
- 171 Txp volume stats
- 172 usefulness

- 173 user and patient friendly
- 174 User friendly
- 175 user friendly
- 176 user friendly to lay public
- 177 Very easy to navigate.
very little, it has taken a bit of adjustment and at times it has been difficult to locate a specific
- 178 resource, mostly on the OPTN view
- 179 Very user friendly
- 180 Vey simple to use
- 181 Would prefer to find everything on one site.

UNOS Website – Improvement Suggestions

Question: What are your suggestions for improving the Website?

Number	Response Text
1	A diagram explaining steps to the process of MPSC review would be helpful.
2	Add a directory of all approved Transplant Centers along with the Transplant Administrators contact information
3	Again, I have not been to the web site, recently.
4	Annotated jumps to specific OPTN bylaws or the evaluation plan. At times, areas are difficult to locate.
5	Better access to the links for allocation policies and first person designation information for OPO staff who use them daily.
6	Clean up policies and bylaws. There is a lot of redundancy and it is difficult to find something that may be needed quickly.
7	Combine UNOS, OPTN and SRTR on one website
8	Confusing to know where to go for what.
9	continue to highlight patient resources
10	Cross link the committee membership
11	data
12	Delay in requesting data using the UNOS website vs. the OPTN website.
13	don't know
14	Easier security administration features to set up new users, etc It is not very user friendly in my opinion
15	Easy redirect to the OPTN web site
16	Every year I complain about the user "unfriendliness" when trying to put a new person on the list to be able to use the website, usually persons associated with HLA and other labs. It is still awful!
17	Get a professional web designer.
18	Go back to a single, consolidated site.
19	go back to the old site
20	go back to the way it was
21	Go back to the way it was.
22	Hard to intuitively navigate
23	Have a more directed page for transplant centers
24	Haven't really thought about it. Would need more time to look it over.
25	Having the policies be searchable would be wonderful.
26	Hiting "enter" to search for an active patient would be better than clicking search
27	I did not use this site before the redesign.
28	I dont use it much use secure site
29	I don't use it often enough to have a specific suggestion.
30	I find it harder to find data and to make a data request with new design.
31	I find it harder to navigate than prior. Patietsns have voiced similar problem and dont seem to reference it as much other than Transplant Living
32	I find the data that I need quickly, and love the multiple options for searching.
33	I have none at this time.
34	I like it.
35	I miss having the Member directory with contact info that used to be on UNOS.org. I have not seen where this data is located on the OPTN website
36	I still struggle with by-laws/policies that are UNOS and those that are OPTN. I wish there

- were a policy tab that would be a jumping point to which site holds the topic you're looking for. (I understand there are links...but not always helpful, still have to hunt.)
- 37 I think it's fine the way it is.
I think that it is more difficult to find information now than it was previously. I personally do
- 38 not like the drop down link as it does not include all areas that may be required.
I think the KPD Pilot program info is kind of hard to find. The brochure is easy to get to, I am
- 39 referring to the guidelines and participating centers, etc.
I would like to be able to access items - especially data - from the main website without being
- 40 redirected.
- 41 I'd have to think more about this.
- 42 If possible 24/7 support
- 43 Improve search engine
It has taken me some time to find the site information that used to be in one place; I am still
- 44 not completely used to this change and often find myself looking on both sites before I find
what I need.
It might be helpful to have a short tutorial on the side explaining where to find things such as
by-laws and policies and why you will leave the UNOS site and are connected to teh OPTN
site. An explanation of who maintains what. As a new director I found that very confusing. I
- 45 really like the new drop down list.
- 46 It was a bit confusing at first
- 47 It's a useful website - no specific suggestions right now.
- 48 Its fine!
It's more difficult to find things on the new site. I'm getting used to it, but it still seems
- 49 illogical.
It's not as easy to find items. There are more than 2 clicks to get to specific pieces. I would
- 50 place the most often used items on the front screen to reduce the number of clicks.
- 51 It's not as user friendly as the earlier version.
- 52 keep up the good work
- 53 links on front page to SRTR data
Maintain the UNOS site when being routed to the OPTN, that way you could toggle back and
- 54 forth
- 55 Make it clear the distinction between OPTN and UNOS by-laws on the website
- 56 Make it clearer when policy changes became/beome effective.
- 57 make it easier to access policies and events
- 58 make it easier to find and get information
- 59 Make it easier to find information in the policies and bylaws -- still a challenge.
- 60 make it easier to find policies and bylaws
Make it friendly for different browsers- My computer updates Microsoft and Firefox that make
it impossible to use from home. I hate having to drive to work on the weekends just to do a
- 61 UNOS function.
- 62 Make it Mac friendly!
- 63 make policies easier available
Make sure that once work orders are completed, to contact the person creating them and
- 64 inform them it is done.
Make the OPTN policy page easier to get to directly . Can't remember the
OPTN.HRSA,transplant.GOV address . Create a UNOS policy link that is easy to remember
so you can go to the policy / bylaw section in the fewest possible clicks. Also, make the
OPTN site look more related to the UNOS site with some similar graphics and colors. The
OPTN looks like a government site. I understand the need to clearly differentiate the two
unos purposes are different corporate and OPTN but the OPTN site looks totally independent
from UNOS. It'sconfusing to the public and most clinical transplant staff who arent familiar
- 65 with the admistrative structure and history of UNOS.
- 66 Make the professional education tools for transplant centers in 1 central location.... webinars,

newsletters, and UNET Tutorials could all be here.
More advertising focused toward potential and actual recipients. A lot of them are unaware it exists as a resource...

67
68 more user friendly, not so many levels to drill into
69 n/a
70 N/A
71 n/a
72 NA
73 NA
74 No
75 No opinion
76 no specific suggestions at this time
No suggestions.

The separation seems redundant as there are individual links on the UNOS website to specific sections of the OPTN website (data, policies, etc.).

77
78 None
79 none
80 none
81 None
82 None
83 None
84 None
85 None
86 none
87 none
88 None
89 NOne
90 none
91 None
92 None
93 None
94 None
95 None at this time
96 none at this time.
97 None at this time.
98 None at this time.
99 None for now
100 none, haven't really thought about it
101 None.
102 None. The website is very user friendly.
103 Not sure
104 Please let Financial Coordinators know which pts are double -listed and where.
105 Policies on the front Page. Don't send us to the OPTN page
106 policy and by laws are still difficult to locate
publish data reports provided to the membership through requests after waiting an appropriate period for the requestor to use the information for publication, etc. . This is public information and everyone might like to review the information.
107 put calendar as a stand alone tab on the front page. The calendar is very helpful when you get to it.
108

- 109 Put them back together.
- 110 Searching for policies/bylaws is still SO difficult. Difficult to the point that when I searched "subtyping" last week, it came up with NO results, but when I typed in "subtype" the information came up. Still couldn't really find what I was looking for. This is very frustrating!
- 111
- 112 Seems hard to find what I need. Not a big fan.
- 113 Sometimes, the search area does not bring you to the specific area of the website
- 114 Speed...site is terribly slow at times.
- 115 SRTR is difficult
- 116 Still difficult to find things via UNOS site.
- 117 The overall website is somewhat difficult to navigate and would benefit from a redesign. users see unos as one entity and getting redirected when accessing policies and procedures
- 118 / bylaws is irritating
- 119 Would love to be able to use the site on a mobile browser for password reset and call notification updates.
- 120 You can never have too many patient stories. I really like the numbers on the front page that states how many waiting and how many transplants have occurred

E-Newsletter—Usefulness

Question: What do you find most useful about the e-newsletter?

Number	Response text
1	A quick glance at the content and link to information I want to access
2	ability to review past items and when they were discussed
3	Access to updated information and notice of upcoming events
4	access and retrieval of info
5	accessibility
6	alert to changes impacting my use of UNET
7	all information is located in one place as trying to hunt down all the emails
8	All of the current information is in one place.
9	any changes to policies
10	articles available, webinars available for educational purposes
11	as an update between meetings. don't always read it or follow links
12	back track notices, policy changes. Information on interpretations and whats new
13	Best Practice Articles and activities of other OPOs
14	Best way to distribute important information!
15	Can read whenever I want to.
16	Cohesive and compact, rather than assorted emails over time.
17	comprehensiveness
18	Concise
19	concise
20	Convenience
21	convenient and accessible
22	convenient to use
23	Convenient way to keep up to date on issues
24	Convenient, although I tend to pass over it with so many other e-mails and then fail to remember to go back and look at it and have missed some things.
25	Current information about policy
26	Current news
27	Current up to date information from across the nation. Great articles and pictures.
28	discussions
29	Ease of access
30	ease of use
31	Easier access, less email
32	easier to assess which articles are relevant to me and which I elect to read
33	easier to track upcoming policy changes. Frequent e-mails often get 'lost in the system'.
34	Easy access
35	easy access
36	easy access to policy changes and reminders
37	easy to access
38	easy to click on links
39	Easy to find and read
40	Easy to find information and links are helpful.
41	easy to find topics of interest to me
42	easy to maneuver and good information
43	Easy to read and access

- 44 Easy to scan summary - let's me focus on the subjects/topics that I need to worry about
- 45 Email delivery & archiving
- 46 Everything
- 47 everything in one spot
- 48 Everything is in one spot. It helps not having a million e-mail updates throughout the month, but having the one newsletter.
- 49 Everything....it's good to keep in the loop
- 50 Excellent review of stuff I might have missed, because I don't get all the emails.
- 51 Feature Articles about Donors and Recipients
- 52 Fewer individual e-mails, everything in one place
- 53 Finding things in one area and not multiple emails throughout the month
- 54 general information
- 55 General information concise manner
- 56 get a great perspective of what is going on nationally at UNOS and our peers
- 57 gives us the up to date requirements
- 58 good information in one place
- 59 Good informative information, quick and easy to review for things I need to know
- 60 good overview of topics
- 61 Good positive information.
- 62 good reminder / update of what's going on w/ UNOS
- 63 Good summary of current happenings
- 64 great communication tool
- 65 great single source of information, don't have to cross reference other sites
- 66 Great way to remain current.
- 67 Has cut down on the number of e-mail notifications
- 68 Having pertinent information in one area
- 69 helpful reminder to check in and useful to engage other staff with information that is pertinent to their departments.
- 70 Helps me feel up to date with ongoing issues/events
- 71 hyperlinks to proposals for public comment
- 72 I am glad a newsletter is sent out.
- 73 I do not care for internet reading. It hurts my eyes. I resent the additional cost to print and the format makes printing difficult.
- 74 I enjoy receiving this on-line.
- 75 I have it with me no matter where I am. Yet I don't have to carry any paper with me. :)
- 76 I like getting the update on what is happening at different facilities and what is happening in transplant as a whole.
- 77 I like having it at my fingertips.
- 78 I like it.
- 79 I like the links and updated info when there are policy updates, or things that are going to change such as things UNOS or CMS will review on an audit
- 80 I love that all the communication from UNOS is collated into the one email. I feel like I'm getting access to the most current information and can reference and read in detail those items of specific interest to me.
- 81 i never receive it
- 82 I rarely read the newsletter as I find it never useful at all.
- 83 I use it for new policy information and learning about policies out for public comment
- 84 information in one e-mail
- 85 informational
- 86 Informative

- 87 informative about the community
- 88 Informative.
- 89 insight
- 90 interesting articles
- 91 It consolidates the information so I can obtain the information more efficiently
- 92 It is a quick highlight of topics
- 93 It is a terrific summary
- 94 It is a wonderful tool to keep updated and easy to link up for more information.
- 95 It is the go-to place for changes that we need to know.
- 96 It lets me know what updates are coming to UNOS.
- 97 It reminds me of upcoming proposals and meetings
It serves as either an "at-a-glance" type document or a thorough review document of
- 98 upcoming UNOS happenings; I always feel I am more up to date when it is released.
- 99 It's efficiency.
- 100 Keep me informed
- 101 keeps me up to date on new regulations
- 102 keeps me updated on the latest news from UNOS and the transplant world
- 103 keeps you abreast of what's going on
- 104 less activity in my inbox!
- 105 little snippets of info
- 106 Love the newsletter!! Helps keep the staff informed in a better format
- 107 makes me feel more confident that I have the most up-to-date policy information available.
- 108 monthly summary of important need-to-know updates
- 109 more up to the point information I may need
- 110 Most current & updated info.
- 111 n/a
- 112 na
- 113 NA
- 114 Nice having information combined into one, instead of multiple emails.
- 115 nice summary of content for that issue. no paper.
- 116 Nice to see what other regions are doing and the different articles
- 117 no specific comments at this time
- 118 None
- 119 not so much junk
- 120 Notices of policy changes
- 121 Notification of the changes in policy and board members.
- 122 One communication vehicle
- 123 One place to locate important information.
- 124 One stop shopping for information
- 125 Policy and procedure help
- 126 policy changes, webinar/educational training updates
- 127 policy updates
- 128 policy updates
- 129 Policy Updates.
- 130 Practical info about UNOS resources
- 131 Provides current updates on a real-time basis.
- 132 Puts useful information in my hands.
- 133 Quick access to info
- 134 Quick and dirty (not really DIRTY) news.

- 135 Quick update on current events and policies up for review..
- 136 rarely read
- 137 Really appreciate getting information in this format and not receiving multiple emails.
- 138 Received monthly - concise summary of up to date information/links.
- 139 Reference articles
- 140 Reminders, policy changes, live meeting recordings.
Seeing what is in the publication and using it as a resource for what the hot topics are in the
- 141 country.
- 142 Sharing of information on a national basis
- 143 SHORT, CONCISE AND AUTOMATICALLY COMES TO US
- 144 Sometimes I find useful information or interesting/inspiring articles.
- 145 Stories shared and data
- 146 summary of happenings
- 147 summary of pertinent issues and policy issues
- 148 Synopsis of what's happening
- 149 the links
- 150 The links are helpful
- 151 The news, the guide and all that is going on in the UNOs world.
- 152 The questions that are answered
- 153 The updates
- 154 This is one of the most positive changes UNOS has made. It is much easier to stay current.
- 155 Timely information
- 156 Timely information
- 157 up to date info
- 158 update on policy
- 159 Updates
- 160 updates on policy changes
- 161 updates on policy
- 162 updates on upcoming changes
- 163 Updates; current issues.
- 164 Very handy to be able to refer back to articles.
Wealth of information and the ease of use. In addition, the availability of getting archive
- 165 information with ease.
Well summarized. I am not interested in most of the items, they are too clinical or about
aspects of operations I am not involved in. I can scroll and decide quickly what interests me
- 166 or not.
- 167 You access the articles you are most interested in with out having to read through everything

E-Newsletter—Improvement Suggestions

Question: What are your suggestions for improving the e-newsletter?

Number	Response Text
1	.
2	?
3	Archive with other education resources to 1 location
4	Because I am in Communications, I would love more content about media and UNOS. Differentiate more clearly the differences between minor and major policy changes. Add programming changes so that programs and vendors can make necessary changes in a timely way.
5	difficult to ascertain when critical information is being offered
6	Go back to email
7	good format and useful - no suggestions
8	I don't read it anymore as too much clicking and searching to find an article and way too many choices. I found it easier to get hard copy newsletter or full newsletter send via e-mail so I can read at my leisure without hunting for articles that might or might not be useful/interesting.
9	I find it difficult to find the time to fully read it. I didn't like getting so many individual emails but this is too much information to arrive at one time. I need something that is somewhere in the middle.
10	I have not consistently received the monthly emails. None received in October or November.
11	i prefered indiv emails
12	I think this is a good process.
13	I would stick with important changes in policy that would affect most institutions.
14	improve ability to locate news according to each policy
15	In the month before the BoD is to vote on policy/bylaw changes, please include the list of which changes they will be approving at their meeting. This would give centers a heads up and allow us to start working on forms, informed consent or policy changes that need to be made or created since many times we have to rely on 3rd parties to provide printing/approval of forms or changes (i.e. all informed consents at our center must go through the hospital lawyers before they can be used) and many
16	Include a case study
17	It always goes to spam on my company settings so maybe notify in individual emails about its upcoming mailing.
18	it would be nice to have bullet points in the email as a teaser to read more...
19	It's almost too brief, I stopped getting the Update for some reason, so I feel kind of disconnected.
20	disconnected.
21	It's great!
22	Keep content to that which can impact our work. Articles on donors and recipients are interesting and inspirational, but not necessarily impactful.
23	Keep it coming. I also think you could move towards an electronic distribution of the UNOS update publication to save costs. I would read it as often if it came to me electronically and probably more timely.
24	Let main OPO contact know that everyone receives this because it is remailed here several times.
25	Links often don't work
26	make policy implementation clearer.
27	making it easier to find the documents the article is about

- 28 making it very clear what is new since last newsletter, important deadlines
- 29 n/a
- 30 N/A
- 31 n/a
- 32 n/a
- 33 NA
- 34 na
- 35 NA
- 36 Need to utilize this as the only venue when making changes to policy, etc.
- 37 No suggestions
- 38 no suggestions at this time
- 39 none
- 40 none
- 41 none
- 42 none
- 43 none
- 44 none
- 45 None
- 46 None
- 47 None
- 48 None
- 49 None
- 50 none
- 51 None
- 52 none
- 53 None at this time
- 54 None at this time
- 55 None at this time.
- 56 None at this time.
- 57 None at this time.
- 58 None at this time.
- 59 None at this time. I am glad a news letter is sent out.
- 60 None for now
- 61 None, it is an excellent resource!
- 62 None.
- 63 None. This website doesn't replace Update print publication however.
- 64 Nothing unless you can free up my time for me
- 65 Send a print copy to those who request one.
- 66 sometimes the items don't open useful information, I don't have an example right off hand
of this happening
The flow of the newsletter could be further developed.
- 67 How about a UNOS Portal where members can log on, contact each other, share best
practices, and receive these notifications more regularly?
- 68 unknown
- 69 would be nice to highlight policy updates so that they catch your eye first

Public Comment—Usefulness

Question: What do you find most useful about the public comment process

Number	Response Text
1	.
2	Ability to comment
3	ability to comment on line
4	Ability to express my view
5	Able to comment on proposed policy
6	allows individuals and transplant programs to provide input to potential changes that will impact patient care and possible budget and staffing requirements within the department.
7	articulating ones thoughts
8	at least get to comment
9	At the regional level, it is good to evaluate and discuss about the proposals and make comment based on our regional need and also at the level of national benefit
10	Can't remember-- it's been awhile back.
11	Completeness of info about the proposed policy
12	Convenient and quick.
13	Done before the e-Newsletter came out
14	Don't remember
15	Don't remember
16	ease
17	ease of putting comments in
18	Ease of submission.
19	ease of use
20	Ease of use.
21	Easy
22	Easy
23	easy
24	Easy
25	Easy
26	Easy
27	easy access
28	Easy electronic process
29	easy to do
30	easy to do
31	Easy to do.
32	Easy to submit
33	easy to submit
34	easy to submit
35	Easy to submit
36	Easy to understand
37	Easy to use
38	easy to use
39	Easy to use
40	Easy to use
41	Easy to use

- 42 Electronic submission.
- 43 Ensures that we give sufficient time and thought to potential changes to Policy.
- 44 Fairly easy
- 45 Feeling that I am part of the community responsible for policy development
- 46 Felt that I was able to give some input
- 47 Give you a chance to express your opinion
- 48 Giving voice to the concerns on potential and living organ donors.
- 49 Heard other sides of the issue in more detail.
- 50 I like being able to view others' comments.
- 51 Intuitive and straight forward.
- 52 It could be done electronically
- 53 It is another voice about the issues at hand.
It is easy to complete electronically and the issues are broken out nicely for ease of finding each one.
- 54 each one.
- 55 It is very easy to do
- 56 It was easy to comment.
- 57 It was easy to use.
- 58 it was user friendly
- 59 It worked fine
- 60 just being able to give my input, and encourage others to do the same
- 61 knowing that it will be read
- 62 Knowing that my comment would be thoughtfully considered.
- 63 knowing the suggestions and having input
- 64 made us think about the implications
- 65 makes me feel valued
- 66 most people now prefer emails.
- 67 N/A
- 68 n/a
- 69 n/a
- 70 N/A
- 71 N/A
- 72 n/a
- 73 NA
- 74 NA
- 75 No follow up on the general comments made for a particular process/policy.
- 76 nothing
- 77 Notification.
- 78 Opportunity to opine.
- 79 overall works well
- 80 participation
- 81 Pretty easy to submit
really find it easy to use, appreciate the clear & concise summary as well as the ease at which to see the full section and what is changed in it.
- 82 which to see the full section and what is changed in it.
- 83 simple
- 84 simplicity without losing depth
- 85 Summary of policies out for comment
- 86 That they are eagerly solicited and listened to
that's a difficult one. I am not sure that anything is heeded as policy is so tightly controlled by CMS.
- 87 by CMS.
- 88 The ability to articulate our concerns.

- The ability to ask questions and give input before the policy became required. Allows us to plan ahead for required changes or at least notify management that they have to be aware of possible changes.
- 89 possible changes.
- 90 the ability to participate
- 91 The chance to make my organization's voice heard.
- 92 the ease of use
- 93 The fact that public comment was allowed and taken into consideration.
- 94 The feeling that I helped shape policy.
- 95 User friendly
- 96 User friendly.
- 97 Very easy to put in comments.
- 98 Very user friendly.
- 99 was done at region meeting
- 100 Was easy to do.
- 101 We discussed and submitted as a group.
- 103 We had a group discussion as part of the Committee I'm a member on.
we have submitted from our center; our administrator has collected our comments and submitted

Public Comment—Improvement Suggestions

Question: How would you improve the public comment process?

Number	Response Text
1	"cliff notes" reader on policy changes for civilians who are directly affected and thereby interested parties but do not have the knowledge to interpret industry documents.
2	.
3	Ability to suggest revisions to a particular policy/process. Feedback on other comments and the impact on specific policies by these comments.
4	After responding, I have no idea how others are doing so; I would love to see others' responses, blinded, of course, but perhaps a graph of sorts that shows common responses and the amount each was given...just a thought
5	Anything that can increase responses by recipients or candidates.
6	Continually reaching out so people understand how to do it
7	Do what the public wants
8	Don't understand the time line. Things seem to be out for comment forever.
9	encouragement that anyone can and should comment
10	feedback loop needed to those who actively submitted input
11	Feedback on the final recommendations to the board would be nice.
12	Followup on issues raised and potential resolutions.
13	Good the way it is
14	Greater awareness and info sharing with interested stakeholdersd
15	Grouping into organ-specific categories.
16	I am most interested in the evaluation of the policy. The evaluation piece is not often well developed when the policies are available for public comment. I have found that the evaluation of the policy can be duplicative and burdensome and not in line with the intent of the policy.
17	I do not recolect recieving a notice that my comment was noted.
18	I like it
19	I like the process the way it is.
20	I think it would be good to send direct email reminders as due date approaches; sometimes I lose track of it knowing I have a few months.
21	It is cumbersome to have to enter the demographic information each time when submitting comments on several proposals at the same time.
22	It would be helpful to know what other physicians comment.
23	Make a standard powerpoint that can be posted on the public policy web site and used by members to educate and discuss with staff prior to submitting comments.
24	make sure more people know about it
25	making it easier to access
26	maybe more electronic notices. I know not enough people do not comment which is not your fault, more should get involved
27	n/a
28	n/a
29	N/A
30	n/a
31	n/a
32	NA
33	NA
34	NA - except possibly for helping UNOS members understand who they are representing

- when they do this
- 35 need more representation
 - 36 Need to have some ongoing communication regarding outcome. Once the notification comes out for public comment, you don't hear anything else about it until it is passed by the board. If it doesn't go to the board, it just sort of disappears. It would be nice for some sort of update, such as :due to overwhelming public comment the proposal is going back to committee for further development.
 - 37 NO real human feedback - seemed as if I was communicating with a machine.
 - 38 none
 - 39 None
 - 40 none
 - 41 None
 - 42 none
 - 43 None
 - 44 None at this time.
 - 45 None.
 - 46 None.
 - 47 None...I like the format
 - 48 On occasion I have had difficulty accessing the proposed policies and couldn't comment on something I really wanted to.
 - 49 Open sharing of the comments
 - 50 Our managers and CEO's should be keeping us up-to-date on the need for public opinion.
 - 51 PLAIN LANGUAGE SUMMARY!
 - 52 post all responses on the web site
 - 53 Provide a very short summary of the issue and the options.
 - 54 publicize it even more? perhaps contact more professional organizations that might be interested? You contact ones that are obviously transplant, I think, but there are others that have transplant-related interest groups.
 - 55 Publicize these and allow members to access these from a SYSTEM MESSAGE.
 - 56 Reporting data results
 - 57 Seems we are inundated with messages, emails, e-publications from UNOS these days. In past, there was not so much information being sent to centers. I find it very hard to find the time to review it all so I actually don't anymore. I read info haphazardly when I have time - which is not very often.
 - 58 Send more than just the initial email. Send reminders that the proposal input period is coming to an end..
 - 59 some transplant staff at our institution do not receive the email
 - 60 Speed the process up. Taking two to three years to approve the change often reflects in changes to the changes before implementation.
 - 61 Still cumbersome...but is much better.
 - 62 The Patient Affairs Committee should be more active in explaining to the transplant candidates and representatives that Public Comment is the time to give input--Once its policy, it is too late to change--transplant support groups should use their group functions to submit comments on policies out for comment. The basic transplant candidate does not know or understand they have a voice in how the policies are developed.
 - 63 The policy proposals need to have a date that the proposal opens and closes. The summary pages are great but there is no date anywhere to reference later.
 - 64 To share the public comments
 - 65 when their is only 30 days left in the comment period send a second e-mail time running out to comment
 - 66 When you email the proposals, if there was a better way to distribute them online to staff members who need to review so they could review online easier. We print them & distribute,

- would prefer an easier way to distribute online to our team.
- 67 Would be nice if they could be addressed and we were able to review the responses.
- 68 would be nice to have the option once you've completed making comments to "email" other individuals with the link, encouraging them to comment as well.

Policy Notice—Usefulness

Question: What is most useful about the policy notice?

Number	Response Text
1	. They summarize and include exact policy changes
2	Ability to keep abreast of what's going on
3	Advance notice of changes
4	Again, not written in concise English. Not at all understandable - Needs background of issue and needs to be concise.
5	Alerting me that a policy has been proposed.
6	Alerts me to go out and review the proposals
7	all
8	Allows me to prepare my center for upcoming policy changes
9	allows people to stay informed
10	Appreciate email notices from UNOS.
11	As above, need to streamline the process. I don't understand the steps a proposal needs to go through to be implemented. Seems like it goes on forever and is discussed way too many times.
12	aware that changes are being considered
13	Background as to reason for policy change
14	Becoming aware of changes. I
15	bring your attention to the issues
16	clear - easy to understand language.
17	Clear instructions, links and phone numbers provided.
18	Clearly illustrates changes - easy to follow.
19	cms /unos requirements
20	Communicated through e-mail
21	Concise
22	Ease of access.....
23	Ease of finding them
24	easy to access
25	Easy to access and understand
26	Easy to find notices that directly impact the lab.
27	Easy to read and understand
28	easy to read/understand
29	easy to understand
30	Easy way to stay current. Changes are tracked
31	Email format is very efficient

- 32 E-mail is very convenient, however, I tend to pass over it with intentions to read later, then sometimes forget about it. Also, I personally sometimes get overwhelmed with the changes, the work involved with all of this, compliance etc. with UNOS and CMS. Both need to get on the same page with requirements and policy.
- 33 ensures that txp personnel are up to date with policy changes
- 34 everything
- 35 Finally...they're organized! It was so difficult before when important changes were made but we were only notified by the "typical" email. Bravo!
- 36 find out what crazy thing is trying to be implemented
- 37 focused update and need to know what to do information is critical
- 38 getting in multiple formats
- 39 getting them in email
- 40 gives relevant background
- 41 Gives you a chance to express an opinion
- 42 good summary of what needs implemented
- 43 How they affect allocation
- 44 I don't find them useful at all.
- 45 I get an automatic notice of new policy.
- 46 I like that the notices are sent out far enough in advance to let the staff know of changes
- 47 I like the format you now have where you have the link button on the left and you show the chart of who is affected. That way, I don't have to wade through all of them - only the pertinent ones.
- 48 I like the matrix of what I need to pay attention to, I made read them all but I especially read the ones that affect my teams.
- 49 I read them if it pertains to laboratory practice.
- 50 I skim them
- 51 Informational
- 52 informative
- 53 Informative; and, reminder to review, discuss in internal meetings, submit comments.
- 54 It gives me warning of changes in the data required for Tiedi that I work on.
- 55 It helps me understand my job, what are the expectations and how this affects patient care.
- 56 It helps our program to stay aware of important updates/changes required for our program
- 57 It helps with my committee work and makes me more knowledgeable about transplant initiatives.
- 58 It is a heads up in case I need to evaluate our own internal policies for the change control process; it keeps me up to date and in the loop on compliance issues and PI Opportunities for our staff.
- 59 It is in nice bold type and is easy to read with the help of the matrix.
- 60 It is useful to know that the policy has changed and how it may affect your practice.
- 61 It keeps me updated
- 62 just keeping up and knowing what is coming, though I would wish to read them more carefully
- 63 Just knowing they occurred

- 64 Keep up to date
- 65 keep up with current changes to make sure they coincide with our practice
- 66 Keeping up to date on potential changes to current practices
- 67 Keeping up-to-date on policies being suggested.
- 68 Keeps me abreast of changes pertaining to me and helps to ensure we are remaining current
- 69 Keeps me updated
- 70 Keeps me updated and our center, lab and OPO
- 71 keeps me updated in my practice
- 72 Keeps me up-to-date and informed
- 73 keeps us compliant
- 74 Keeps us up to date
- 75 Keeps us up to date on policy that may affect our practice
- 76 Keeps us updated. Without these it is difficult to now the changes because so few staff can attend the UNOS Regional meetings or Forum
- 77 Keeps you in "the know".
- 78 keeps you up to date and allows practice consistent with new policies
- 79 Keeping up to date
- 80 Lets me know of policy changes
- 81 lets me now i need to look at our internal work flow when the policy takes affect.
- 82 Link to area from the overview page
- 83 links to language and the chart ot show who is affected by the changes
- 84 maintaining compliance in an ever changing regulatory world
- 85 Memory jogger. Reminds me to review changes.
- 86 n/a
- 87 NA
- 88 new updates are defined
- 89 Nice synopsis without having to read the comprehensive version.
- 90 nice to know if we need practice changes
- 91 nice to see what is being changed
- 92 plain language
- 93 Ready access
- 94 receiving new/current information
- 95 **Response Text**
- 96 Short, important points about policy
- 97 summaries
- 98 Summary
- 99 summary info
- 100 that they exist!
- 101 The "nutshell" content
- 102 The "what I need to worry about" section.
- 103 The ability to provide input on decisions being made.
- 104 The advance notice
- 105 The direct communication of what I need to know
- 106 The links are convenient. You can look for ones that apply to your institution quickly.
- 107 The more I see them the better.
Whatever form they come in.

- 108 The summary titled "What you need to do"
- 109 The way they are delivered. You don't have to go looking for them.
- 110 They are a necessity to remain in compliance.
- 111 They are informative regarding changes.
- 112 They tell you who should be aware of these actions so you can find the pertinent information.
- 113 thoroughness
- 114 Timely; frequent.
- 115 track changes,
- 116 Updating centers on what is in progress
- 117 Very thorough
- 118 Very well organized and developed. Like the grid to easily identify which groups are impacted by each policy. The links attached to each policy change summary is very helpful.
- 119 Well it's better to know than get a surprise
- 120 well organized and provides good background info
- 121 With busy schedule of most of the people involved in transplantation these reminders are great way of informing people
- 122 With email notification, very specific and I share the ones which apply to our laboratory and the organs we transplant
- 123 Yes

Policy Notice—Improvement Suggestions

Question: What are your suggestions for improving the policy notice?

Number	Response Text
1	.
2	a prominent summary of the practical impact of these notices. not so many technical details to get lost in.
3	Again very hard to access and too many of them.
4	again, keep very focused on what is new/required and what to do with it. there is so much to be aware and know, so overwhelming!!!
5	Always include which organ groups are affected
6	Appreciate email notices from UNOS.
7	Clear summary of changes
8	create a standardized summary powerpoint available on the OPTN site that could be used to educate and update staff
9	Difficult to copy and paste sections of the policy
10	Difficulty in navigating to the policy for discussion.
11	Easier format to take a quick glance..
12	Find a way to have in a very short executive summary
13	Gosh there is so much and we are busy trying to take care of the patients.....
14	Have an office secretary write them in plain English and then have them edited by an English major to make them concise. DO NOT have a lawyer or bureaucrat touch them.
15	I have none at this time.
16	I know you have people writing these trying to make them easy to understand, however, the verbage is very lengthy and not all that specific to real practioners. Also, many obvious unintended consequences are not addressed in the write up which is why some get signifcant negative feedback. This could be avoided up front with better review from e
17	I still like the paper book!
18	I think the notice is fine...I am not sure at times UNOS 'gets it' as far as the sheer volume of policy changes and how hard it is to make corresponding internal practice and policy changes- and how to hardwire the new practice in a program. I think sometimes UNOS staffers wonder "geez, why didnt this program do this - the policy changed two years ago" but again, its so hard to keep up with all the regulations we face when UNOS is the one regulator who makes such frequent released changes.
19	I want a clear final copy of the policy without strikethroughs and additions.
20	I would like every policy that is changed to come to my e-mail as a user to know there is a change. Also the policies are hard to read with the strike out lines through everything.
21	Line by line comparison with previous/existing policy and citation of relevant Federal regulations.
22	make it short and sweet
23	Make them less cumbersome to read. It's difficult to find time to read a notice that links you to 50 pages of policy edits.
24	making the policies easier to read

- 25 Maybe increase the frequency or change the format so it is easier to get through the information.
- 26 More concise explanation of the policy, and how it will affect the specific area involved (i.e. allocation, registration, regional sharing, etc.)
- 27 More precise language that explains how we can realistically implement the changes. Also, the format seems scattered. You have to follow a good bit of links and then aren't sure if you've viewed everything. Easy to miss things due to the volumes.
- 28 N/A
- 29 n/a
- 30 NA
- 31 NA
- 32 Need to be written in plain concise english. Who, what, when , where, how. Make it simple. They are written almost as if you are trying to hide something. example: Modifications to Clarify which Transplant Program has Responsibility for Elements of the Living Donation Process and to Reassign Reporting Responsibility for Living Donation from the Recipient Transplant Program to the Transplant Program Performing the Living Donor Nephrectomy or Hepatectomy
- 33 none
- 34 None
- 35 None
- 36 None
- 37 none
- 38 None
- 39 None
- 40 none
- 41 none
- 42 none
- 43 none
- 44 None
- 45 none
- 46 none
- 47 None
- 48 none
- 49 none at this time
- 50 None at this time
- 51 None at this time
- 52 None.
- 53 Nothing
- 54 nothing at this time
- 55 please remove all the strike-outs in the policy from past versions--it is so hard to read
- 56 Policy and bylaw info hard to find
- 57 put them in basic language - good work by UNOS for putting all of them into public language that is easier to read and understand. Eliminate initials
- 58 see above
- 59 Send by email or print and snail mail.
- 60 Shade alternating columns...it is hard to follow them vertically on a screen.

- 61 Simplifying the language for the non-health care professionals who may wish to comment.
- 62 Smaller file - takes too long to load.
- 63 some are too lengthy
- 64 Stick with e-newsletter. Highlight change in the newsletter.
- 65 The changes need to be more plain language.
- 66 The language is difficult to understand-especially when sections are struck out.
- It is also sometimes difficult to determine whether the policy is in effect or pending.
- 67 The language is not always clear so maybe additional examples of what it could mean in a real event setting
- 68 The language used could be more easy-to-understand rather than referencing policy numbers.
- 69 The policy notices are almost never applicable to my concerns.
- 70 There needs to be less steps to get to the meat of the policy.
- 71 They are most helpful when there are implementation dates or estimated dates.
- 72 This may not apply to me.
- 73 various role specific updates...
- 74 very lengthy; difficult to immediately ascertain whether it relates to my position
- 75 when changes to policy affecting tx ctrs occurs and need to be implemented-would be useful to have it highlighted in the notice and decent lead time for implementation would be helpful
- 76 Wider distribution to non management

System Notice—Usefulness

Question: What do you find useful about the system notices?

Number	Response Text
1	Again - I haphazardly read these notices. Often the same notice is there for months.
2	Again, allows me to stay up to date for compliance of our OPO.
3	Again, direct communication
4	Being current of the changes.
5	Brief and to the point.
6	Catch your attention
7	changes
8	Clear information, phone number provided
9	concise instructions/discussion.
10	Concise, with references to view if further info is needed
11	Convenient and automatic
12	current updates for implementation
13	Describing the audience so that I know if the information pertains to my job description.
14	Ease of access.....
15	easy
16	easy access
17	Easy access
18	Easy to determine if it is relevant to me.
19	Easy to determine which apply to our lab practice
20	Easy to keep staff current because they can just be forwarded to staff.
21	easy to read/understand
22	easy to see what is pertinent and sharing this information
23	Effective Date of the change and what our center needs to do.
24	Email is a good tool to use for these notices.
25	emailed directly to me; concise and easy to assess if they relate to my position
26	getting them in email so I can read them anytime I have a few extra minutes
27	helps me stay informed.
28	I answered no because I was not able to open the "system notice" for review. I can prepare for changes in Tiedi by attending live meetings when provided. It is easy to sign up for these.
29	
30	I do not access UNet, so this is my only notification
31	I find most useful when receiving notification about current update and changes.
32	I have the ability to view all the important notices on UNET or as they are delivered via email.
33	I like seeing what other programs are doing.
34	I like that they are available by both email and on the front page of UNET
35	I read them if it pertains to laboratory practice.
36	I send these notices to the individuals that are affected by these changes If they are useful to the OPO I will read them but if they are primarily affecting transplant centers I am more likely to skip over them unless it deals with the transplant specific programs we serve locally (currently only kidneys)
37	
38	Inform you in advance so you are aware of what and when it is going to happen.
39	information
40	information

- 41 information
- 42 Informs me of up to date changes.
It brings things to my attention so that I make time to read them. Otherwise, I never seem to
- 43 have time to independently go to the site.
It is helpful to receive the notice without having to go to the web site. I am not always on the
- 44 site so its helpful to get something.
- 45 It provides you with the notice before it happens
- 46 Its automatic, it pops up for me, its simple and easy to read and makes me read it.
- 47 keep s me updated on other issues beside those involvin thoracic tx
- 48 keep you updated
- 49 Keeping current with upcoming changes
- 50 keeping my practice up to date
- 51 Keeps all up to date
- 52 Keeps me informed of current information.
- 53 Keeps me up to date
- 54 Keeps me updated
- 55 Keeps up to date
keeps you updated with new information.
- 56 good when policy date of implementation is reached
- 57 Learn about changes
- 58 like being informed - need to read to stay current w/ practice / compliance
- 59 Makes you aware or reminds you of deadlines, changes or system updates.
- 60 May impact operations
- 61 N/A
- 62 n/a
- 63 N/A
- 64 NA
- 65 Need to stay updated.
- 66 Nice and clear
- 67 no comments
- 68 Not to be behind of the game.
- 69 nothing
- 70 Nothing in particular.
- 71 notification by e mail is great
- 72 Notification of time periods in which UNET service may be interrupted.
- 73 notified of high impact changes.
- 74 One more reminder
- 75 pertinent updates affecting listing and allocation issues
- 76 plain language!
- 77 Policy updates and UNOS " down time" affect my practice - good to be kept aware
- 78 READILY AVAILABLE
- 79 receiving updated information
- 80 relevance to clinical practice
- 81 reminder to check for current updates.
- 82 Repitition;
- 83 somewhat helpful.
- 84 Staying abreast of changes and compliance policies
- 85 that they come directly to my e-mail and I do not have to go anywhere to look for them.
- 86 The advanced reminders in stages.

- 87 The information is always clear and probably as concise as could be expected.
- 88 The way they are delivered
there should be another choice besides yes or no for numbers 31 and 32 - I would say
- 89 "sometimes" is more accurate.
- 90 They are right there when I log in
- 91 They are the first thing you see so they are hard to miss.
- 92 they are there to help me keep up with my job
- 93 They can help me, as our lab's IT liaison, to make changes to accommodate UNOS changes.
- 94 They have reminders
- 95 They keep me updated
- 96 timely
- 97 to the point
- 98 to the point
- 99 Too busy; learn policy changes at team mtgs
- 100 updates
Usually do not take the time to read the notices posted (other than UNET downtime
- 101 messages) because I am actively working on a case when it pops up.
- 102 Well organizes, succinct
- 103 When applicable, they keep us informed
- 104 Yes

System Notice—Improvement Suggestions

Question: What are your suggestions for improving system notices?

- 1 (I do not log onto UNet, so this question is not relevant, but surveymonkey forces me to respond.)
- 2 .
- 3 Any system notice that is extremely important, should include a notification to that effect.
- 4 As an I.T. person, the system notices almost never apply to my needs & concerns.
- 5 Change heading to red font
DonorNet outages to be labeled as urgent to differentiate from general announcements to
- 6 announcements that affect operational allocation
- 7 Find a way for them to stand out from the other email we receive.
- 8 Font is hard to read sometimes
- 9 For some reason nothing grabs my attention to read them so I forget.
highlight the new notices in anything other than the gray blue they are current displayed in. gets lost
- 10 and doesnt flag me to read them when i am logging in to do a diffent task
I did have a few questions one time and called the help desk. The assistant did not know the details
- 11 of the notice and could not answer my questions right away.
I do not log into UNet on a regular basis so I often do not see these. I prefer recieving them as
- 12 email.
- 13 I don't think I'm getting all of them.
- 14 I have none at this time.
- 15 I like the emails.
I suggest using a different color font. The current grey is a bit bland for important notices, and could
- 16 easily be disregarded.
I think the notice could still be put in to a shorter paragraph so that a user can skim quickly and
- 17 determine whether this notice is for them.
If it is on a log in page on UNOS, I will probably just click to the next page to get to what I am doing,
and ignore messages. Perhaps you should put in bold a few key words so we can see if it pertains
- 18 to us.
- 19 Just a lot of them!
- 20 Larger font, less white space wasted.
- 21 Making the language more clear to understanding rather than spoken in legal language.
- 22 N/A
- 23 n/a
- 24 N/A
- 25 n/a
- 26 N/A
- 27 NA
- 28 NA
- 29 No need to email, I read them when I log on
- 30 no suggestions at this time
- 31 none
- 32 None
- 33 None
- 34 none
- 35 none
- 36 none
- 37 none
- 38 none
- 39 None

- 40 none
- 41 none
- 42 none
- 43 None
- 44 None
- 45 None
- 46 none
- 47 none
- 48 None at this time.
- 49 None.
- 50 nothing
- 51 plain english,
- 52 Read the emails sometimes, Read them more when they are on the log on.
- 53 the answer to all of the above is sometimes, when relevant to my area of expertise
- 54 The font is hard to read
- 55 The intended audience is frequently misleading and not consistent with actual practice.
The notification is haphazard; the "target audience" is sometimes a subset of people who need to get the information. In the past 5 years, there have been at least 2 major disruptions that we have identified during donors because advance notification of programming changes was not received by the appropriate individuals.
- 56 The reason I checked no to 31 and 32: I do not receive these notices, as I am not with a transplant center, but rather am with one of the coordinating centers for the KPD Pilot Program. However, once the KPD program is automated, I hope to receive these notices!
- 57 There are too many notices, I wish they could be managed better and make all the changes once a month (if possible...understanding some cannot wait.)
- 58 They seem complicated to understand on the surface.
- 59 They seem fine as they are to me
- 60 they're great.
- 61 This may not apply to me.
- 62 use them more often!
- 63 VERY CONFUSING WITH THE NUMEROUS DATES GIVE ME THE ACTUAL DATE THE RULE OR POLICY APPLIES NOT THE DATE THE DECISION WAS MADE ETC...
- 64 Write in English. Avoid ALL abbreviations and jargon and make concise.
- 65

UNOS Primer—Usefulness

Question: What did you find most useful about the UNOS Primer?

Number	Response Text
1	.
2	All of the information was useful in one form or another.
3	All the presentations Number 36 doesn't make sense
4	best learning session that i have attended in my 24 years. extremely helpful and wonderful presentations
5	Better understanding of the different departments and ability to meet with staff
6	everything! very informative
7	Excellent
8	Excellent information. I have attended
9	Extremely helpful to fully understand the way UNOS and OPTN "works".
10	Focused material and face to face meeting of UNOS staff
11	Found it very interesting.
12	Gave a terrific overview of the multiple departments and body of work that is UNOS.
13	Great information! It made it a lot easier to understand the organizational setup. Who's who. This conference had the most job related information for me than any other I've attended.
14	Great to meet people that I have spoken with on the phone.
15	Hands down - the best 2 days I've spent in my transplant career getting clarity about the role of UNOS in transplant.
16	Have never attended
17	Having the contact with the UNOS representatives-
18	helps with understanding UNOS function and committee processes
19	I attended in 9/2010 - it was excellent
20	I have encouraged my administrators to attend
21	I have not attended due to budget restrictions.
22	I have sent a number of my staff who find the broad perspective of the meeting helpful; prior to attending most only interacted with UNOS in a narrow/limited way.
23	I love it. The Primer was awesome. Understanding UNOS's role as it relates to the government was helpful. I think it all connected the dots. As a director I never really understand the role of UNOS. This was a great experience and I would highly recommend attendance from all transplant staff.
24	I think it was very useful but was focused on the transplant center. One needs to be done focusing on the OPO side.
25	I went to the first one. It could have been broken down even further - some of the things were over my head and has taken me a while to get up to speed.
26	Information on structure of OPTN, history of UNOS, information about data reporting (Jennifer Milton's Talk)
27	Intimate setting at the UNOS office in Richmond; opportunity to put face with a name; group and one-on-one time with staff, thumb-drive take-home of presentations.
28	It was an excellent event. Being new to transplant I learned about the Evaluation Plan and now I access several times a month.
29	It was great information
30	It was so helpful especially being new to transplant. I attended and it was GREAT!

- 31 It was useful to see the Transplant Center side of things being an OPO employee; I understand much more of their processes and how UNOS fits into the transplant side of donation and transplantation.
- 32 Learning about the policies, and being able to ask questions.
- 33 Meeting with all the UNOS representatives
- 34 More insight into the transplant world. Getting to put a face on the many folks I've corresponded with.
- 35 n/a
- 36 n/a
- 37 n/a
- 38 N/A
- 39 NA
- 40 NA
- 41 NA
- 42 na
- 43 NA
- 44 NA
- 45 Networking - the content of the meeting was excellent.
- 46 Networking with other center staff and meeting UNOS staff.
- 47 OPO track was nice
- 48 Primer is useful. Would not attend having been on various OPTN/UNOS committees
- 49 Sent by CAO as a new employee and she enjoyed it
- 50 Sent staff to meeting. Found it helpful
- 51 Staff we have sent find them very helpful. Basic information and education about UNOS and data collecting/reporting.
- 52 The explanation of UNOS/OPTN regulatory oversight process
- 53 The UNET portion
- 54 this is critical for the younger staff
- 55 very helpful for committee members to understand the workings of UNOS and the role in creating policy
- 56 We sent a staff member who felt it was heavily oriented to transplant centers as opposed to OPO's
- 57 Where to find reports, accurate teidi reporting

UNOS Primer—Improvement Suggestions

Question: What are your suggestions for improving the UNOS Primer?

Number	Response Text
1	.
2	Ask people to introduce themselves to the group. Develop a game where folks have to find their "secret" partner through asking a series of questions throughout the Primer, like a mystery game... this will force people to speak to one another. I still think Transplant professionals are a "cliche" group.
3	Concerning that a UNOS "Primer" would take 1.5 days. Most of us don't have the time.
4	Consider adding more best practices
5	Consider making it more relevant to OPO's. Consider making an abbreviated version available as a webinar so more staff could be exposed.
6	Have a UNOS for Administrators to attend- review TIEDI Reports and utilizing the Evaluation Plan
7	Have it more often than twice yearly
8	heard great things from my colleague who attended
9	Hold more frequently. Hold it at least once in each region - or targeted regions. How about start with Region 5? :-) I would send all the nurses I could spare. As an Administrator - it is the best way to get the message across to nurse coordinators the importance of policy compliance. My nurses are on a rotating schedule to attend until 100% have attended. That's how well I think of the UNOS Primer.
10	I had several suggestions for improvement which I passed on in a phone interview after the event.
11	I heard that it is awesome
12	I plan on attending in the future.
13	I would make it a 2 1/2 day seminar and include the OPO side; I was looking forward to that and felt that OPOs and their interaction with UNOS was not dually represented.
14	I would love to see this offered as a webinar series to be able to expose more of my staff to this information. We have limited budget and cannot afford to send everyone to the seminar.
15	invite a speaker to also give an overview of the key differences in CMS regs and OPTN rules. Although UNOS cannot speak to this, administrators have finite travel budgets and a fuller perspective of this would be a better benefit to those attending.
16	Is this for OPO too? ...or just transplant.
17	Let people know about it - was unaware of this.
18	Make it a webinar to eliminate travel costs.
19	Make one specific for OPO's. I gained a lot of knowledge even though it was directed for Transplant Centers. However one for OPO's in mind would be wonderful!

- 20 Make the content easier to obtain without traveling to Richmond. The primer content is extremely useful and should be more easily accessible to a larger group of clinical transplant professionals that may not be able to attend. Need help developing a system for ongoing staff training related to OPTN/UNOS regulations and compliance.
- 21 maybe a Primer 2.0 for those who have attended the first and want to continue learning.
- 22 More crossover topics for the OPO side and Transplant side to improve process and communication
- 23 More hands on group work and less lectures. I liked when we had to find the policy.
- 24 More information for OPOs. Maybe one Primer for OPOs and one for Tx centers
- 25 More OPO focus.
- 26 n/a
- 27 n/a
- 28 n/a
- 29 N/A
- 30 n/a
- 31 NA
- 32 NA
- 33 NA
- 34 NA
- 35 NA
- 36 none
- 37 none
- 38 none
- 39 None
- 40 None
- 41 none, I enjoyed it very much, very informative
- 42 Notify all staff members of clinical transplant facilities, coordinators, and other interested parties of its availability and cost.
- 43 Offer more.
- 44 Once a quarter - so more staff can attend.
- 45 OPO specific primer
- 46 Out Data Coordinator attended and endorses the UNOS Primer 100%.
- 47 Provide this as a covered expense for UNOS committee members to attend.
- 48 Question was asked at last Regional meeting if these meetings could be held in each region to diminish travel time/ expenses for those wanting to attend...
- 49 Should have a UNOS Conference for Administrators
- 50 The interactive sessions were really good.
- 51 Unfortunately we could not register due to 'space'. It would be helpful if there was an indicator of # of seats available when you look at the registration information on the website.
- 52 what is it?
- 53 Would love to help with this

Online Training Topics—Organ Allocation

Question: If you are interested in online training about allocation policy, which specific organ types are you interested in?

Number	Response Text
1	All - you can never not receive any reinforcements
2	Kidney and Liver
3	Kidney and liver
4	kidney, liver, pancreas
5	kidney, liver, pancreas, heart
6	liver, kidney, pancreas, heart

Online Training—DonorNet

Question: If you checked DonorNet functionality, what specific features are you interested in?

Number	Response Text
1	1. More user-driven queries and reports to obtain donor specific characteristics, etc. and the ability to download or copy the resulting data in spreadsheet format.
	2. Ability to inquire on a donor based on the UNOS Donor ID specifically without having to enter the match run number.
2	3rd party functionality.
3	A good tool to train new staff for using donornet to assess donor information and a separate session for how to investigate allocation process in using Donornet time stamps.
4	ability to access match runs without match ID.
5	acceptance time and evaluation time.
6	accessing information
7	All
8	all
9	all
10	All
11	all
12	all
13	all
14	all aspects
15	All aspects
16	All- I would like a detailed training session-
17	All the above
18	All.
19	any
20	Any changes and updates to the system.
21	As a data specialist for whom DonorNet is a new application, I would be interested in all aspects.
22	Attachments, browser support
23	Automated crossmatching
24	basic info
25	being able to view images
26	Best practices for utilizing
27	cannot identify specific items at this time, but for functions that are not routinely accessed, or provide more "advanced" functionality would be helpful
28	Changes in data
29	changes to make it more user friendly and effective
30	closing match runs (current tutorial needs to be expanded upon)
31	codes for refusal explained further
32	compatibility issues with Mac computers and mobile devices
33	continuous improvement
34	Donor chart attachments, specifically uploading of radiologic studies

- 35 donor heart preservation
- 36 electronic offers, what does the transplant center see when the OPO sends offers?
- 37 everything
- 38 everything
- 39 Everything.
- 40 extending offers
- 41 General info
- 42 general information to make sure I am utilizing everything efficiently
- 43 General information for use by Histocompatibility lab staff.
- 44 general refresher for staff who work within the DonorNet system . Need a way to verify staff competency within DonorNet system.
- 45 General use.
- 46 having the different OPO's filling in information the same across the board so that people accessing the information on smart devices can get the information necessary
- 47 heart
- 48 How does it function, when no ABO is put in?
- 49 How it interacts with our patient tracking software. (I did attend the uploads class last year.)
- 50 How the OPTN can make donor data accessible without having to send all that paperwork. Copies and copies, etc. that requires a lot of resources and manpower.
- 51 how to customize reports and really use the system better
- 52 How to look up testing results.
- 53 How to use it better
- 54 How to use it to my advantage by knowing what each application is useful for.
- 55 I do not know how it functions.
- 56 I think you should be able to view attachments on your hand-held device. Why does the system allow for continued allocation of organs that have >XX hrs CIT to the opposite coast? You can set lab parameters and distance parameters, why can't you set cold time upon arrival parameters? Also, why don't you have an electronic link to Sterling Courier that allows us to check flight arrangements w/o bothering the UNOS call center?
- 57 Improvements especially for increasing utilization
- 58 Improving allocation process for marginal organs
- 59 issues pertaining to donornet's incompatibility with current IE browsers and how users are working through this
- 60 just basically how to navigate / get info
- 61 Just overall view of what we can and cannot do.
- 62 just tips to see if there is anything that I could do more efficiently
- 63 kidney paired donation
- 64 Laboratory aspects; might be a good adjunct to our current training for new techs.
- 65 Liver
- 66 look-up and reports
- 67 making modifications
- 68 Match Run

- organ offer
- 69 Mobile access
- 70 Mobile device access
- 71 mobile phone
- 72 N/A
- 73 n/a
- 74 NA
- 75 NA
- 76 offers
- 77 Organ Allocation
- 78 Organ allocation & placement - I would like to see more specific details posted on UNet such as anticipated donor OR time and whether or not donor blood samples were sent for crossmatch.
- 79 Organ Offers
- 80 overall--do not work with it on a frequent basis so do not keep up with newest updates and recently got a mobile device but unsure how to adjust settings to access complete DonorNet vs the mobile application that automatically comes up when logging on to site
- 81 Overview for data coordinators.
- 82 Pressor use area
- 83 PTR code(no sera or positive crossmatch) entry for labs that bypass the transplant programs.
- 84 report availability and program specific generation
- 85 Reporting, searching...etc.
- 86 Required fields
- 87 result uploads
- 88 Review of donor offers.
- 89 Staff do not understand the implications of fields in Donornet. Plus we were trained once, I am sure there are features that we do not even know about.
- 90 Staff training aids.
- 91 Standardizing language, abbreviations and having the info in chronological order. Accuracy of info needs to improve a bit. Like smoking history, often different answers in history, narrative note and answer to > than 20 PPY. Should just have PPY total and if stopped when.
- 92 Tiedi Reports and how to accurately complete it-
- 93 To have training specially to everything Donornet can do that I'm unaware of, i.e. reports
- 94 Training of new staff and potential certificates of training completion
- 95 Understanding how it works
- 96 updates occurring
- 97 uploading images
- 98 Ways to easily obtain information
- 99 working in the lab need to know who was transplanted and which donor.
- 100 XML uploads

Online Training—UNet

Question: If you selected UNetSM as an online training topic, which specific elements are you interested in?

Number	Response Text
	1. More user-driven queries and reports to obtain our recipient data and the ability to download or copy the resulting data in spreadsheet format. The current method of Exporting Tiedi data is cumbersome, especially since the reports do not come with headers.
1	2. The ability in WaitList to customize reports that pull data from all of our wait listed patients, not just those currently on the list.
2	Import/export; file validation steps
3	NA
4	Tiedi forms, guidelines for collecting/entering data

Additional Educational Topics

Question: Please indicate any other education topics you would find useful.

Number	Response Text
1	Any major changes in UNOS or CMS requirements.
2	Any new policies
3	anything on living donation
4	Anything to help us get through a UNOS living donor survey
5	Background for new employees on the UNOS and OPTN list and numerical designation etc..
6	basic info
7	Comparison of CMS & UNOS regulations
8	Criteria for status one listing.
9	Culture reporting, I find coordinators don't understand enough about reporting cultures/why it is done
10	DDR compliance-the instructions are not helpful. Would like more information what UNOS would like. Would like language agreement between DonorNet & DDR completion. Would like improved "streaming" between DonorNet and DDR reporting site.
11	Distribution of OPO data
12	Expand a bit on giving a good offer utilizing UNet - have transplant surgeons presenting to OPO folks on how to do this well.
13	Exporting Reports
14	Extra-Renal identification and use of marginal donors. How ischemic times effect live donors transplants outcomes, that are allocated via local, regional and national methods
15	Financial support regarding food, travel, lodging and meds expenses for Puerto Rico and Virgin Island patients
16	Guidelines for follow up and monitoring post transplant for recipients.
17	Guidelines of the new Living Donor UNOS audit and what are the most important things to be focusing on.
18	Heart/VAd
19	Hospital Development as related to allocation and donation
20	How members can use data to drive quality/process improvement initiatives
21	I think I may need some fairly basic education. My knowledge base regarding UNOS is very limited.
22	If webinars are used, please archive in a single location to be found later by staff if they cannot attend the live presentation.
23	Impact of Adverse Events on Transplant Centers
24	information on preparing for the CCTC exam
25	Is there a standard application of Karnofsky's scoring relative to kidney TX candidates--patients may still be working, dialysis centers now have nocturnal dialysis which allows patients to work/attend school
26	Management of donors
27	Maybe there should be regular webinars for new policy proposals in addition to the PDF proposals
28	MMFI cut off, what they really mean and how different labs interpret them.
29	More education on compliance and understanding the policy

- 30 More in-depth donor management best practices
- 31 n/a
- 32 n/a
- 33 NA
- 34 NA
- 35 NAT testing and HLA testing
- 36 No
- 37 organ allocation training
- 38 organ preservation / perfusion
- 39 Paired donation
- 40 Patient safety incidents - are we reporting them all? Can we do better? - education
- 41 Policy interpretation
- 42 PR/public education, media, donor family/recipient communication, volunteerism/activism
- 43 requirements for status qualifications heart
- 44 RFI preparation. Understanding policies & by-laws.
- 45 something about legislative topics, organ transportation and policies in the US that hinder or help the safe and efficient movement of organs or the organ center itself
- 46 Standardization would be very helpful. If you are a kidney program basic standard policies and protocols for everyone especially with the QAPI programs.
- 47 TIEDI Reports- and how to complete-
- 48 To review "problem" policies that seem to be most common among centers nationally.
- 49 transplant finance
- 50 Transplant management best practices
- Financial management - HMO and Medicaid
- 51 Understanding SRTR data and how it ties to UNOS reporting
- 52 UNOS structure
- 53 Use of the on line data tool
- 54 Webinar addressing the latest policy revisions/new policies along with best practice suggestions from centers
- 55 Yes. After attending the PRIMER it appeared that the amount of time required to participate on a committee was much more than I could ever volunteer for. As an OPC, I am already on call >70 hrs a week. We are a small OPO! It doesn't mean I don't want to participate, but time is precious. Are there less time-consuming/demanding things to participate in?

Volunteer Contact Info

Question: If you are interested in serving on a committee or work group or would like to teach or develop an educational session, please give us your name and contact information.

Number	Response Text
1	David Hull, MD, FACS Also was on the OAC and also Vice Chair and Chair Now serving on the MPSC and Associate Counsellor of Region 1
2	Brenda Thrasher 704 355-8071 brenda.thrasher@carolinashealthcare.org
3	Karen Hess, RN, MS, MBA, ACNP (702) 671-1029. Karen.hess@umcsn.com
4	Betty Hunter hunterbj@upmc.edu
5	susan hall shall@ctdn.org
6	Victoria Vollbrecht tvollbrecht@core.org 800-366-6777 x271
7	Giorgio M. Aru, MD University of Mississippi Med Center (601) 984 5176 garu@umc.edu Programs and literature to educate patients from underdeveloped areas
8	Colleen McCarthy colleen.mccarthy@bcw.edu 414-937-6961
9	Paul Kroner; email: pkroner@stanfordmed.org. Thanks!
10	Cheryl Edwards RN MSN CCRN 203 232 8288 Particular interest in disease transmission and ethics
11	lisa florence MD lisa.florence@swedish.org 206-386-3660 issues related to kidney transplantation
12	Jenny Lee jenlee@stanfordmed.org
13	I'm already on a subcommittee for KPD, but would be interested in other committees. Laurie Reece, 512-961-6199, laurie.reece@paireddonation.org
14	Sheryl Moore, BSN, RN Lifepoint 843-763-7755
15	Jennifer Muriett 602-222-2498 jennifer@dnaz.org

- 16 Nance Conney
520-694-7367
nance.conney@uahealth.com
- 17 Sharon Walls
509-474-4702
sharon.walls@providence.org
- 18 n/a
- 19 Esther-Marie Carmichael, 714-330-2982, esther-marie.carmichael@med.usc.edu
- 20 Kim Phillips
(843) 792-0280
phillk@musc.edu
- 21 Judy Baker
214-82-8863
judyba@baylorhealth.edu
- 22 Charles B. Huddleston, MD
314-268-4183
chuddle7@slu.edu
- 23 I have offered to serve on the OPO committee, but the process for how members are selected is confusing. Dina Steinberger, UW OPO dsteinberger@uwhealth.org, 608.265.0374
- 24 James Pagan
phone: 801 641 9941
email: james.pagan@hsc.utah.edu
- 25 Deonna Moore, MSN, ACNP-BC
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- 26 schaffer.randolph@scrippshealth.org
- 27 Julie Traub
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(702)383-2224
- 28 Janet Mize-Jugert RN 210-7005-6702
janet.jugert@christushealth.org
Administrative operational activities
- 29 silas norman
spnorman@umich.edu
734-763-9041
Content-allocation, outcome, encouraging donation
- 30 already serving
- 31 elizabeth hemedinger ehemedinger@immco.com
- 32 Linda Grinnell-Merrick, NP
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585-273-3756
- 33 Patricia Adams
padams@wfubmc.edu
- 34 Lisa Martin, e-mail lisa.martin8@va.gov, phone (804) 675-5403

- 35 Anna Gonzalez
Director of Information Systems, Donor Resource Center, and Kidney and Pancreas
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- 36 Deirdre McAdams
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- 37 Amy Evenson
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- 38 Leslie Semones
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- 39 shelina merali
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404-550-0275
- 40 Jeanette Ohm / johm@giftoflifemichigan.org
- 41 Cynthia Laws
407-644-7030 x 261
Cynthia.Laws@translife.org
- 42 Linda Munro
313-916-2271
lmunro1@hfhs.org
- 43 Kelly Ranum
kranum@lopa.org
- 44 Tamara Nunes
tnunes@ctdn.org
- 45 Henry Randall, MD
Associate Professor of Surgery & Immunology
Director, Abdominal Transplantation & HPB Surgery
Saint Luke's Hospital of Kansas City
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MP I, Suite 240
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816-932-4655
hrandall@saint-lukes.org
- 46 Giorgio M. Aru, MD
2500 North State st
Jackson, MS 39216
- 47 Kandi Byrd
813.844.5521
- 48 Karen Krok
215-349-8222
karen.krok@uphs.upenn.edu
- 49 Lori Markham
lmarkham@mwn.org

- 50 Frank Rathman
Donor Alliance
(303) 501-6272
frathman@donoralliance.org
Would be willing to help with what ever I can
- 51 Donna Smith
Mid-America Transplant Services
dsmith@mts-stl.org
- 52 Marlene Abe
marlene.abe@stjoe.org
- 53 Mary Nachreiner
mnachreiner@uwhealth.org
One project that comes to mind is establishing a brochure on how to write your donor family
(unless there's one I couldn't find online)
- 54 Ramon A. Cruz-Castro, MSW
787/ 763-0104
cruzr@dneph.com
- 55 Ray Gabel, BA
Midwest Transplant Network
913-261-6145 rgabel@mwn.org
- 56 Paul Gaglio pjgaglio@montefiore.org
- 57 Tammy Wright, 858-650-5016, tammy.wright@sharp.com
- 58 Becky Harris-Burns
248-551-1035
bburns@beaumont.edu
- 59 Pamela Thiessen
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- 60 Brett Loehmann
901-328-4466
bloehmann@midsouthdonor.org
- 61 William Hasskamp
828-777-1761
whasskamp@att.net
- 62 Fadelle Powell, BSN
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- 63 N/A
- 64 Laurie Rose, MPH
800-535-9206
OPO: Life Connection of Ohio
lrose@lcodro.org
- 65 Lisa Allen
319-356-8877
lisa-allen@uiowa.edu
- 66 Karen Walker
walker@umich.edu
- 67 Gloria DeMattio (614)384-7345 gdemattio@lifelineofohio.org
- 68 Rose Chappell
margaret.chappell@baylorhealth.edu
214-820-7699

- 69 Maureen Miller
mmiller@harthosp.org
860-545-3938
I would be interested in anything to do with the KPD program or testing.
- 70 Ryan M Lehoullier
New England Organ Bank
617-558-6607
ryan_lehoullier@neob.org
- 71 Robert Cirocco PhD
610-402-8121
robert.cirocco@lvh.com
- 72 Linda Letourneau, RN, CCTC
774-442-5274
Kidney/Pancreas patient education
Work w/others to develop ed project.
- 73 michele_prod@rush.edu
I supervise an HLA lab that does not do deceased donor testing. However, if you think I could be of assistance with something, please contact me.
- 74 sharon.burford@emoryhealthcare.org
- 75 Laurie Z. leder, LCSW, CCTSW
laurie.leder@uch.edu
- 76 Isabel Neuringer
660 Beaver Dam Road
Chapel Hill, NC 27157
919-260-2242
- 77 Randall Heyn-Lamb, RN
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- 78 Christine Lee, RN, BSN, CCTC
cdlee@mednet.ucla.edu
- 79 Stacia Hays, ARNP, CCTC
mccras@shands.ufl.edu
- 80 Nicholas R DiPaola
614-293-8554
- 81 Meelie DebRoy
meelie.debroy@utsouthwestern.edu
- 82 Tracy Giacoma
816-945-6012
tgiacoma@kumc.edu
- 83 John Abrams, 215 557 8095
- 84 I am currently on a UNOS committee and participate in a work group. I enjoy this very much and find it very interesting
- 85 I already serve on a committee.
- 86 can't at this time I would love to participate however we are very understaffed and currently there is no time
- 87 Nancy P. Ford, LCSW
904.956.3205
ford.nancy@mayo.edu
- 88 I already serve on a committee.

- 89 Brigette Marciniak-Bednar RN CCTC
Bbednar@JHSmiami.org
305-355-5155
- 90 Leslie Simmons
leslie.simmons@memorialhermann.org
- 91 Charles B. Rosen, MD
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- 92 George Chau, MD
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- 93 Luis Mayen
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- 94 Jason Hopper-Cruz
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- 95 Sabrina Ho
DMV & Media Relations Specialist
(213) 229-5674
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- 96 Am already on the PAC committee.
- 97 Crystal Peeples, 313-587-5197, cpeeples@giftoflifemichigan.org
- 98 Jan Folsom
jan.folsom@imail.org
- 99 Edie Chan, MD
edie_y_chan@rush.edu
- 100 Carlos F. Zayas, M.D., F.A.S.N., F.A.C.P.
Chairman Department of Transplantation
Carlos and Maguerite Mason Endowed Chair in Transplant Medicine
Director of Transplant Nephrology
Medical Director of the Renal and Pancreas Transplant Program

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email: carlos.zayas@piedmont.org

- 101 Charles Wright
charles.wright@lifelinkfound.org

- 102 Audra Lopez
Nurse Practitioner - 954-712-3939

- 103 I already serve on a UNOS Committee as a regional rep

- 104 Christina Block, RN. christina.block@mountsinai.org, 212-659-8097
- 105 Ben Keebler 214-755-5953 bkeebler@organ.org
- 106 Alexander Gilbert
alexander.gilbert@nyumc.org
212-263-2692
- 107 Am an active serving committee member already
- 108 Melissa Roberts, MSN, RN, CPTC
mroberts@surgery.bsd.uchicago.edu
Professional or patient education; I am also a transplant recipient.
- 109 Alexander Kuo
Alkuo@ucsd.edu
619-543-2675
- 110 I am already a member of a committee and several work-groups
- 111 Melissa Blevins - Administrator - Mayo Clinic in Arizona - Blevins.Melissa@mayo.edu 480-342-2691
- 112 Sukru Emre, MD
203 785-2565
Sukru.emre@yale.edu
- 113 (I'm on the living donor committee but willing to serve in other ways too). Mary Amanda Dew, 412 624 3373 dewma@upmc.edu
- 114 Dorrie Dils
ddils@lifelineofohio.org
- 115 Schawnte' Williams- Taylor
8066980651/8067985568
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Organ Procurement or Minority Affairs
- 116 Ann Satterly
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- 117 Judy Flores
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- 118 Jamie V Bucio
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- 119 Melissa Korb RN,BSN,CPTC
Transplant Administrator/Transplant coordinator
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419-383-6795
- 120 Marilyn Downs
mpdowns@swmail.sw.org
- 121 I am already on several UNOS committees

- 122 Nicole Johnson, RN, MBA,
Quality Regulatory Program Manager
Annette C. & Harold C. Simmons Transplant Institute
214-820-7718 phone
214-818-8105 fax
NicoleM.Johnson@Baylorhealth.edu
- 123 Marian Charlton, 212-746-1742, mbc2001@nyp.org
Living donor or paired exchange
- 124 Lan-Phuong Vu-Yu
125 Darla Phillips, RN, MSN, CCTC
919-681-9857
darla.phillips@duke.edu
Currently on Ops and Safety Committee
- 126 Paula Gull
Paula.Gull@stjoe.org or 714.771.8033
Would be interested in health promotion post op for either recipient or donor
- 127 Cindy Zarate 734.922.1264 czarate@giftoflifemichigan.org
- 128 Mia Hunter, RN, BSN, DCS
mhunter@lifegift.org
- 129 Scott Pritchard
707-773-1355
Topic - transportation (air/ground)
- 130 Barbara York, OPC; The Center for Donation & Transplant; byork@cdtny.org. Best practices for uploading images to SoftMD. This DOES result in more organs transplanted.
- 131 Angie Korsun
813-844-4907
akorsun@tgh.org
- 132 Heather Purvin, Gift of Life Donor Program
hpurvin@donors1.org
- 133 Lauren Quinn
518-262-9543
lquinn@cdtny.org
I am open in terms of developing content. Have extensive writing experience.
- 134 Vicky Young, PhD
(928) 350-3200 office
vyoung@prescott.edu
Living donor issues especially psycho-social, spiritual, disenfranchisement, advocacy, and long-term research on donor wellness.
- 135 Jennifer Carapellucci, RN
Jennifer.carapellucci@allkids.org
- 136 Jennie P. Perryman, RN, PhD
Jennie.Perryman@emoryhealthcare.org
404.712.4993
Content - living donor follow-up; disease transmission, CMS and UNOS - roles of each, etc, etc, etc.

- 137 Colleen Marchand
colleen.marchand@jeffersonhospital.org
educational projects pertaining to heart transplant
- 138 Carolyn Light, 415-735-1144, carolyn.light@ucsfmedctr.org
- 139 Donna Esposito, RN, CCTC Office 281-275-0307 on Tuesday & Wednesday Office 832-522-8256 on M, Th, Fr.
- 140 Burton J. Mattice
734-660-7337
bmattice@giftoflifemichigan.org
- 141 charles patrick
organ preservation / perfusion consultant
chpatrick@yahoo.com
- 142 Kim McMahan
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Would like to help develop a High School Education and Awareness Program
- 143 Mary Theresa Massey
502-629-7944
mary.massey@nortonhealthcare.org
- 144 Cyndy Kirschbaum, ckirschbaum@giftoflifemichigan.org, 734-922-1270
- 145 Sharon Swofford, MA, RN, CNN, CCTC
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- 146 Roxannr Taylor, Rn, MSN
Living Donation Coordinator
Maine Transplant Porgram
Maine Medical Center
207-662-7185
taylorm@mmc.org
Anything to do with living donation or the exchange program
- 147 Bill Thompson bthompson@giftoflifemichigan.org
- 148 Scott A. Brubaker, CTBS; Chief Policy Officer - AATB; 703.229.1040; brubakers@aatb.org;
UDHQ-OTE Project
- 149 Karen Malagrino
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- 150 Already on committee
- 151 Lstocks@ucsd.edu
- 152 William L. Freeman, MD, MPH
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wfreeman@nwic.edu
[NOTE: I am on the Living Donor Committee
- 153 Jacqueline Harris, RN, BSN, CCTC
flyin-nurse2701@sbcglobal.net.
I am a former transplant coordinator, working for Astellas the past 11 years.
- 154 Anissa Cole 804-332-3701 Anissa_Cole@lifenethealth.org
- 155 Susan Zylicz
713-441-5481
szylicz@tmhs.org
- 156 Heather Yergen, MBS, BA, CTBS. Gift of Life Donor Program, Philadelphia, PA. email:
hyergen@donors1.org

- 157 Msumlin@thellf.org
Melanie Sumlin
- 158 patient education project-stacey.thompson@hsc.utah.edu
- 159 thoulel@lifechoiceopo.org
- 160 Esther-Marie Carmichael 714-330-2982
emcarmichael@sbcglobal.net
esther-marie.carmichael@med.usc.edu
- I'd be willing to help in any way possible; I'm an experienced presenter and trainer.
- 161 William McTague wmctague@cdtny.org
- 162 Ginger DeLario
gdelario@carolinadonorservices.org
- 163 Cheryl Pedigo, RN
uknursecheryl@gmail.com
859-983-7607
- 164 Linette Meyer
651.603.7845
- 165 Katrina A. Bramstedt, PhD
txbioethics@yahoo.com
www.transplantethics.com
- 166 Julie Morgan
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jmorgan@onelegacy.org
- 167 Nicole Patterson
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patternr@ihs.org
Kidney
- 168 Kelly Peterson-Short, RN, BSN, CCTC
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- 169 Elmira Wozniak RN CCTC
480-342-1010
wozniak.elmira@mayo.edu
- 170 Carolyn Quin Alexander
214.820.6857
carolyn.alexander@baylorhealth.edu
I would be glad to assist in an education packet focused on post transplant.
- 171 Cecilia Huffman, 904-444-9742, huffmc@lifequest.ufl.edu
- 172 Donna.smolen@osumc.edu
- 173 Barbara Nuesse
203-688-6731
barbara.nuesse@ynhh.org
- 174 Sam Hill
Organ Donation Manager
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- 175 Carie Kadric' RN
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- 176 Mike Kaiser 319.665.3787
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- 177 Lucienne Case
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402-559-5000
- 178 Felicia Castro
Email: fec9001@ny.org
- 179 Jeffrey P. Orlowski
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jorlowski@cdtny.org
- 180 Mary Ann Palumbi RN,BS,CCTC
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317-338-6701
- 181 Kathy Schwab
507=266-2795
- 182 J. Tham Hoffman RN, MSN, CCTC CPTC
jhoffman@kumc.edu
- 183 PJ Geraghty, pj@dnaz.org (my participation in UNOS activities is well-established)
- 184 Audra Hutton Lopez ARNP, MSN
alopez@browardhealth.org
- 185 Marion Stewart - currently on TCC committee
marion.stewart@duke.edu
- 186 Pre-transplant educational efforts. Heart transplant related care after the procedure.
Bonding among transplant recipients. Social awareness activities.
- Merle Zuel
785-550-9771
zuel@mac.com
- 187 Kathe LeBeau, kathelebeau@gmail.com, 518-785-5283 (already a PAC member until 2012;
willing and interested in serving in other capacities going forward)
- 188 Julia Hart
julia.hart@lcnw.org
- 189 An
- 190 Kim Hermie
kbhermie@hotmail.com
- 191 Jeannie Malatesta
515-241-4178
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- 192 Jane Benjey, BSN, RN, CCA
234 Goodman, ML 0726
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- 193 Laura Butler
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- 194 Jennifer Johnson, 708-327-2883, jennjohn@lumc.edu

- 195 Dean Henderson
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- 196 Dr Jimmy A. Light
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202-877-6029
- 197 Pam Gillette, MPH, RN, CNN
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- 198 Tracie Singleton
843-792-0722
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- 199 John Hodges, 617-943-4399, jcfh@alum.mit.edu
- 200 Patrick Giordano
TXSA
- 201 Dave Gee
Director of Information Services
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- 202 Itzia Iglesias - imeza@coh.org
- 203 danika medina
telephone 713-202-1057
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Willing to participate / develop / deliver content
- 204 Mary L Walter
757.388.4293
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- 205 melanie.alford@utsouthwestern.edu
- 206 Deborah Pierce BSN,RN,CCTC
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- 207 Nick Feduska, 310-794-8689, nfeduska@mednet.ucla.edu
- 208 Meghan Henderson
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- 213 Walt Nickels
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- 214 .
- 215 Marge Frueh, Transplant Administrator UCH
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- 216 Anne Murphy 734 764-4141 annemurp@med.umich.edu
- 217 Jerita Payne
jerita.payne@vanderbilt.edu

Final Additional Suggestions

Question: Do you have any final additional comments?

Number	Response Text
1	.
2	<p>1. E-mail communication from UNOS to broad audiences is not always appropriate. For example, recently an e-mail requesting confirmation of UNET administrators was sent to dozens of people in my organization. Not only did those authorized to sign the document receive the e-mail, but many others as well. This led to duplicated effort and lots of explaining. I would ask that e-mail groups be reviewed and specific audiences targeted.</p> <p>2. UNOS maintains a member directory of individuals at each center - but this directory is not accessible to centers. It is hard to keep it up to date when we are unsure what is in it.</p>
3	<p>All UNOS contacts should have alternate options in their out of office emails. Some UNOS staff will have an out of office that simply states they are out of office without any other options for assistance.</p>
4	<p>As a data professional, I am very interested in using the wealth of data that UNOS collects to improve the operational processes that my OPO uses. Unfortunately, the data is deeply inaccessible. The ad-hoc query tool is clumsy, limited, and labor intensive. Submitting a data request takes so long that the answers are almost always irrelevant by the time they are received. Besides which, they give me only one snapshot in time. I frequently refer to UNet as a "write-only memory". I want a way to get to data programmatically, securely, and without human intervention.</p> <p>Whenever I call UNOS for technical support, I get the distinct impression that UNOS does not care about my difficulties. I would like to have access to a problem escalation procedure. I would also like to start right off at level 2 support - by the time I am calling, all the easy stuff has been tried.</p> <p>I find UNOS to be opaque and mysterious. I have not had the opportunity to attend the Primer, but what I really want is to have an ongoing relationship with well connected people there. Other vendors that I spend a lot of money with have set up a weekly conference call with our OPO staff. Given the importance of UNOS to our operation, I would like at least the same with you. Such a relationship would go very far toward alleviating my frustration with UNOS.</p>
5	<p>Because I'm not with a transplant center, sometimes I don't get all the notices that indirectly affect our organization. For instance, Dr. Rees received notice that the KPD program was becoming integrated w/ UNet in Dec. This is really important to me, as the main contact for our coordinating center (APD) but I didn't get the notice.</p> <p>Overall, I think UNOS does a great job of maintaining all of the policies and infrastructure that make transplantation possible.</p>
6	<p>CAN YOU DO BUSINESS WITHOUT THE PATIENT'S SS#? THAT IS THE NUMBER 1 HIPAA ISSUE W/IN OUR INSTITUTION ...NO SS # YET UNOS HAS THEM ALL OVER. YIKES!!</p>

- 7 For me the tutorials are not beneficial, i am very hands on type and appreciate a structured teaching environment. i do better with interaction.
- 8 Have an option of NA for Donor Family Member who is not working for an institution using the UNOS tools for organ and tissue transplantation.
- 9 have been heavily involved with UNOS since its creation and still is. My major complaint and concern today is that UNOS is not governed by a Zero Risk mind set that is harmful to the patients. this mindset is promulgated by CDC, FDA, CMS and other agencies - who all believe it is their charge to protect the patients from us, the professionals. it is time for the professionals to begin to protect the patients from the bureaucrats, patients are losing their lives because of thoughtless policies forced upon us. the most recent donor transmission policies are case in point. all the professional organizations turned them down, refused to sign on but the policies are still pushed. It is time to relegate the non-transplanters to advisers and not desicion makers - this includes the "politicians" form CMS/HRSA
- 10 How about a national transplant recipient conference? Bring as many recipients together as possible and share common experiences and collective knowledge.
- 11 I am interested in finding out what Transplant centers tell recipient's about their donors and promoting a standardization of that process. This should be done collaboratively with the OPO's.
- 12 I find it very difficult to find policy info when I am looking for a specific topic. For instance, there is not a lot of info about combined kidney/liver. It would be easier if there was an index instead of having to scroll thru many policies. (The policy #'s don't help if you don't know which one that you are looking for. A guide in straightforward language that delineates things such as what is absolutely required for listing, etc would be great. I know that the info is there, but the system is not user friendly.
- 13 I find it very discouraging that UNOS does not provide anyone to interpret policy. If these are your policies that an OPO needs to follow there should be someone avaiable to interpt the meanings of these polies rather tyhan saying its the OPO's choice but then they cal still get in trouble.
- 14 I find submission of content to UNOS update to be extremely difficult and the editor to be hard to access. Since it really is the only widely read industry magazine, people and organizations want to share their news through it. I'd this is not the right portal, intentions of the publication need to become more clear.
- 15 I had to click yes to complete the survey and some of these items to do pertain to me such as policy notice etc.
- 16 I just attended the DonorNet seminar in Charleston. This was very well done. Could we have a similar seminar about other XML uploads: e.g. DDR?
- 17 I think directors / managers should encourage involvement / education re: UNOS .
- 18 I would like improved mobile device options on Donornet. I would like to be able to change the person on call from my Iphone, open donornet attachments, see all test results. In reality, I would like to be able to see all screens.
- 19 I would like to know more about your review classes--when, where are the held--since new at administration would like to learn more-thanks
- 20 I would love to be on a UNOS Committee
- 21 I would love to suggest that password reset be available to all members via personal challenge questions or through a text message token number. This would cut down on calls to help desk and give users alternate recourse.
- 22 I'm from a Canadian OPO. Inclusion would be great. I can not answer many of the questions above as it does not pertain to us.

- 23 I'm very glad you did this survey. Thank you for the opportunity to provide user/customer feedback.
- 24 In order to interpret my responses. I am on a UNOS committee. This question was not asked earlier.
- 25 I've seen a lot of development over the years to improve the process for patients and transplant professionals. Thanks for the continued interest in making the donation and transplant process better for everyone.
- 26 Keep up the good work!
- 27 Keep up the good work! I love UNOS :)
- 28 Make the UNOS Regional meetings a webinar format so travel isn't required
- 29 n/a
- 30 NA
- 31 NO
- 32 no
- 33 No
- 34 no
- 35 No
- 36 No, keep up the good work!
- 37 No.
- 38 None
- 39 None at this time
- 40 None at this time.
- 41 none, and thank you for this opportunity to rate your services.
- 42 not at this time
- 43 Not at this time
- 44 Not at this time
- 45 Not at this time
- 46 not at this time.
- 47 Not at this time.
- 48 Only that I enjoy my work with the use of the UNET/UNOS system because its so user friendly and the help/support I get from the people at UNET is very efficient and most of all wonderfully excellent! I raise my hat to them all:))
- 49 Please fix the search function for policies/bylaws!
- 50 Programming for automatic declines in DonorNet for recipients over 1000 on the PTR
- 51 Regarding UNet---would just recommend consistency in data provided and uploading all important studies and reports (ECHO, CXR, CT scans, EKG, cath etc.).
- 52 Shorter surveys, even if they have to come more often.
- 53 Thank you, the website is overall a great resource for donor management and follow up and the help desk staff and organ center staff are great
- 54 Thanks for everything!
- 55 the reason for decreased survey response is because I received one almost exactly like this - from UNOS I thought - and almost deleted this e-mail. Just FYI.
- 56 The UNOS/OPTN Policies could be written better. I believe I read that someone on the UNOS staff is reviewing them and evaluating them for clarity. Sentence structure used throughout needs review and improvement.
- 57 There is a lot of complexity of the OPTN/UNOS, SRTR, and HRSA and also overlap and also specific requirements of each. These should be simplified and their differences easily referenced. Also review of how payors and patients use all this and if meets the goals of the various oversight organizations, Transplant Centers, Labs, OPO's etc.

- 58 UNOS is an incredible organization overall. Thank you for the work you do for the field of transplant
- 59 UNOS leadership needs to listen to committee recommendations, and advocate for them, especially when HRSA capriciously moves to block them.
- 60 UNOS should be more representative of the transplant community, less of a quasi-government bureaucracy, more interested in helping patients with renal disease and "sharing organs" and less of a "big brother" intruder.
- 61 Update the Help Documents for each Form. There are places on the Help Forms that need to be more specific to help centers stay compliant.
- 62 update your learning modules in the resource section of UNet--some are from 2005
- 63 When a patient transfers to a non-participating center, it is necessary to put in a ticket to get them removed from our site. There is no drop down option to use. (In the past, we could use ZZZZ, but that is now for transfer to a foreign country). Thanks.
- 64 When opening match runs, have it automatically open with 100 potential transplant recipients rather than only 20. It wastes a lot of time to have to change it every time when you've already passed sequence #20 during placement.
- 65 When running reports in Waitlist...the ability of the app to 'edit' elements of the requested report without having to input all the data all over again.
- 66 Would appreciate follow up on this survey, and again followup on outcomes of public comments.
Appreciate the request for input.
- 67 Yes--PLEASE restructure the application process for primary surgeon/physician. The paper application is cumbersome and a tremendous waste of resources. This could easily be made into an online process that would be much more efficient.
- 68 You are doing a great job and thank you for soliciting community ideas for improvement; Great Move!

