ORGAN AND TISSUE DONATION EDUCATION INITIATIVE FOR HIGH SCHOOL YOUTH

A COLLABORATIVE EFFORT OF THE GIFT OF LIFE, MISSOURI DEPARTMENT OF HEALTH AND SENIOR SERVICES, DEPARTMENT OF ELEMENTARY AND SECONDARY EDUCATION, MID-AMERICA TRANSPLANT AND THE GOVERNOR'S ORGAN DONATION ADVISORY COMMITTEE

HOSA STUDENT FOCUS GROUP RESULTS: MARCH 2017



BACKGROUND

The LifeSavers™ Program was developed by the Gift of Life (GOL), Kansas City and is a high school education program about organ, eye and tissue donation. The purpose of the program is to inform students and encourage families to discuss organ, eye and tissue donation, build public awareness and acceptance about the value of organ, eye and tissue donation, and ultimately reduce the number of patients waiting for a transplant.

When the LifeSavers™ Program was developed, technology that is available today was nonexistent, and while the program reached high school students in the counties of Adair, Benton, Cass, Clay, Jackson, Lafayette, Platte, and Ray counties, it is cost prohibitive to expand beyond these counties.

The Organ and Tissue Donor Program within the Department of Health and Senior Services (DHSS), the Governor's Organ Donation Advisory Committee (GODAC), Department of Elementary and Secondary Education (DESE) and the Health Occupations Students of America (HOSA) Missouri leadership, and Mid-America Transplant wants to expand the LifeSavers™ Program. The statewide strategic plan, *Saving and Enhancing Lives*, high school education priority goal is to "Educate and build awareness about organ, eye and tissue donation so people can make an informed decision." The associated objective is to "increase the number of high schools implementing the Gift of Life program."

In order to go beyond these eight counties, program materials need to be in a format that various subject matter teachers, student groups, facilitators/presenters, etc., can readily implement and that grab the students' attention while being informative. Data is necessary to determine student perceptions across the state and teacher input is necessary in order to re-tool and expand the LifeSavers™ Program. This report focuses on student perceptions.

METHOD

In order to develop an effective program that provides a variety of options to Missouri's autonomous school districts, data is required to make an informed decision. The student population targeted for focus groups was Missouri students that are members of HOSA and that plan to attend the spring HOSA conference in March 2017. The goal was to have 70-100 students of the nearly 1,000 expected to attend divided between seven focus groups. Actual number of students that signed up to participate and had permission from their parent(s) was 70. Of the 70 students, 44 participated in the focus groups. Facilitators had word that some students were not in attendance due to illness. It is also thought that some students who signed up to participate were unable to do so due to a possible conflict in their HOSA schedule or chose not to participate that day. Student participation was voluntary.

Students were recruited by DESE through HOSA Chapter Advisors (page 21). Focus group session size was limited to 15 students per focus group and each student that signed up and had a parental release form (page 22) was assigned a session time by DESE. Each session lasted 45 minutes. DESE provided parental release forms, organized by focus group, to the focus group facilitators and facilitators checked student attendance against the forms. Any student who did not have a parental release form was not allowed to participate. Release forms were returned to DESE. Facilitators met several times prior to the focus groups to discuss process. A tip sheet was provided to each to assure process consistency (page 23). The room number for focus group sessions were published in the HOSA program. In addition, an announcement was made during the opening session. No incentives were provided, though focus group facilitators did oblige students who asked for their HOSA participation card to be signed after each focus group session.

Facilitators were divided among the seven focus groups and an assistant was provided to take down information provided by the students. Facilitator tip sheet, qualitative questions (paper and cards), markers, and the data collection tool (pages 25-27) were provided to each facilitator/assistant in a packet. Each facilitator assistant was given a flip chart with the questions written out for ease of recording responses. Facilitators encouraged students to be open and honest and informed students that they were not required to answer questions if they did not want since participation was voluntary. The facilitator read each question or statement out loud and engaged the students in conversation and observed reactions and interactions to help facilitate discussion while the assistant wrote down the responses to the questions (pages 8-20). Responses and data collection did not jeopardize the student's identity, liability, financial situation or their reputation.

The high school student focus group qualitative data was reviewed by the facilitators for completeness and analyzed by DHSS Organ and Tissue Donor Program staff. Student demographic data collected was age, race/ethnicity, gender, school type, grade and county of residence. No student names or other personal identifiers were collected as part of the focus groups. The data collection tool used protected the students' identity. No audio recordings were made. No individual school data was collected. All data in this report are aggregated and become the shared property of GOL and the DHSS Organ and Tissue Donor Program. Data will not be published; rather, the data shared will be used for public health practice (e.g., the development of a program for high school students).

SUMMARY

The HOSA student focus groups data collection is part of a collaborative effort of GOL, DHSS, DESE, Mid-America Transplant and GODAC to expand the LifeSavers™ Program. Utilizing focus groups to collect self-reported organ, eye and tissue donor related information about attitudes, beliefs and educational learning styles of high school students was recommended by DESE. Data collected is being utilized to inform program decisions, resource development and implementation of a high school education program for school districts throughout the State of Missouri.

Students that participated in the March 2017 focus groups are interested in health occupations. On more than one occasion a student would say "we know more than the average student," and heads would nod in agreement around the room. While most statements provided by these students were accurate and indicate they are knowledgeable about organ, eye and tissue donation; there still appear to be some myths that need to be addressed as program expansion development continues. In other instances, they had the information partially correct. Many of the students were directly affected by organ, eye or tissue donation, aware of someone in their school that was directly affected, or had a close friend that was directly affected. It is unclear if the average student, that is students not pursuing a medical career, would respond in the same manner to the focus group questions as the HOSA students.

Nearly half of the students in the HOSA focus groups indicated they have discussed their wishes about organ, eye and tissue donation with their family or a loved one. These students wanted their loved ones to know in the event of an accident; they did not want their parents to be surprised. Those students who have not spoken with their family either did not respond or, had a variety of reasons not to engage in conversation (page 14). This is an opportunity for the team to incorporate how to discuss the topic of organ, eye and tissue donation in a non-threatening way. Only eight, or 18 percent, of the students indicated they did not learn about organ, eye and tissue donation prior to obtaining their driver license. It appears that students who have enough information choose to be donors and document that decision at the local license office.

Students were adamant that education needs to begin in the 8th and 9th grades. HOSA students thought broadly and outside of the box when asked in which class would they want to discuss organ, eye and tissue donation. Students provided multiple ideas, including social studies, sociology, debate, English, etc., which needs to be taken into account when developing the LifeSavers™ Program expansion. Other suggestions included community centers, sporting events, blood drives, the HOSA conference and Facebook. Multiple avenues have been suggested by students to assure that they are educated about organ, eye and tissue donation. While 18 students want the learning format to be by a rally with speaker, the traditional way the LifeSavers™ Program is taught, the majority of the focus group members, 26 students, choose other options, including assembly and peers (page 18). This is an indicator that program expansion needs to be comprehensive and flexible to fit a variety of learning venues.

Forty-four HOSA conference students participated in one of the seven voluntary focus group sessions in March 2017. The student demographics, pages 6-7, indicate that the largest student group was adults (age 18), with the second largest age group being 17. Forty of the 44 students were either in grade 11 or 12; two years older than the age group that the high school education project plans to target in order for students to speak with their family and make an informed decision about donation prior to obtaining a driver permit/license. The majority of the students were white with some representation from other race/ethnic groups, except for Native Hawaiian or other Pacific Islander. All but one student was from the public school setting and more females than males participated. Consideration should be given to surveying the general student population vs. HOSA students in order to get a clearer understanding of what the average Missouri high school student knows and expects in a learning experience. The following pages contain the HOSA student demographics, focus group responses and a summary for each focus group question. Large portions of Missouri's youth were not represented in the focus groups. Thirteen, or 29.3 percent, of focus group students reside in a county already receiving the LifeSaversTM Program, which may have skewed the focus group results. Areas not represented include Northeast, Northwest, City of St. Louis, and Southeast Missouri; and to some extent Central and Southwest Missouri.

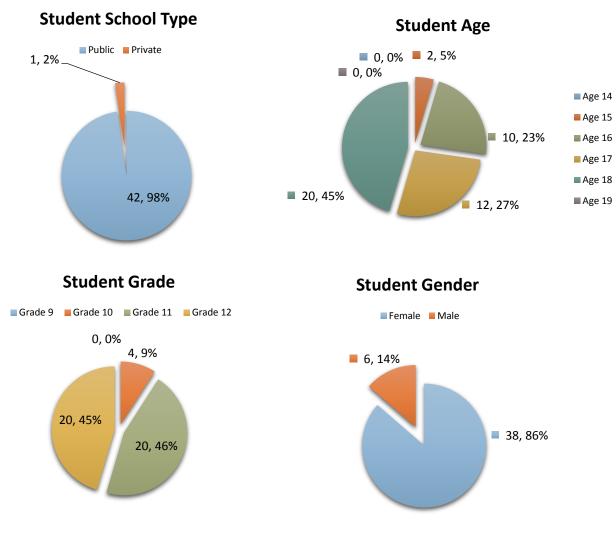
An unexpected outcome of the focus groups was that the information gathered can help direct future HOSA conference workshops and competitions; students made several suggestions on how organ, eye and tissue donation can be incorporated. The DESE has a unique opportunity to incorporate student ideas into future HOSA conference educational experiences.

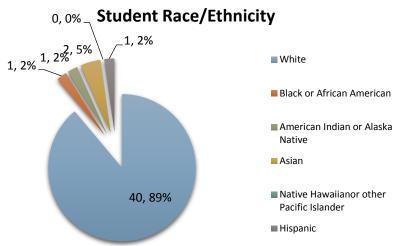
Does the average student, not pursuing a career in health care, know as much about organ, eye and tissue donation? Did the focus groups reach the right age group? According to some of the students, the answer is no to the average student. With nearly 30 percent of the focus group students already being exposed to the LifeSavers™ Program, HOSA student feedback, age of focus group participants, and geographic gaps, some of the facilitators question whether enough data has been collected from students in order to develop LifeSavers™ Program materials that will meet educational needs across Missouri. To assure that a more global understanding of what the average Missouri high school student knows, how to learn, and wants to learn about organ, eye and tissue donation, the DHSS recommends additional student input be sought through focus groups, online survey or by other means. To determine the best method of reaching additional students, DHSS recommends seeking counsel from DESE on how to obtain additional data.

What has been learned from the participating HOSA students is that they expect accurate information delivered in a simple manner; they want the facts so that they can decide if they want to be a donor or not and what to donate. Also learned is that information presentation styles varied. The DHSS recommends that the high school education project team consider a comprehensive program that contains a variety of learning options. By doing so, schools, teachers and students may have more of an opportunity to participate and learn about organ, eye and tissue

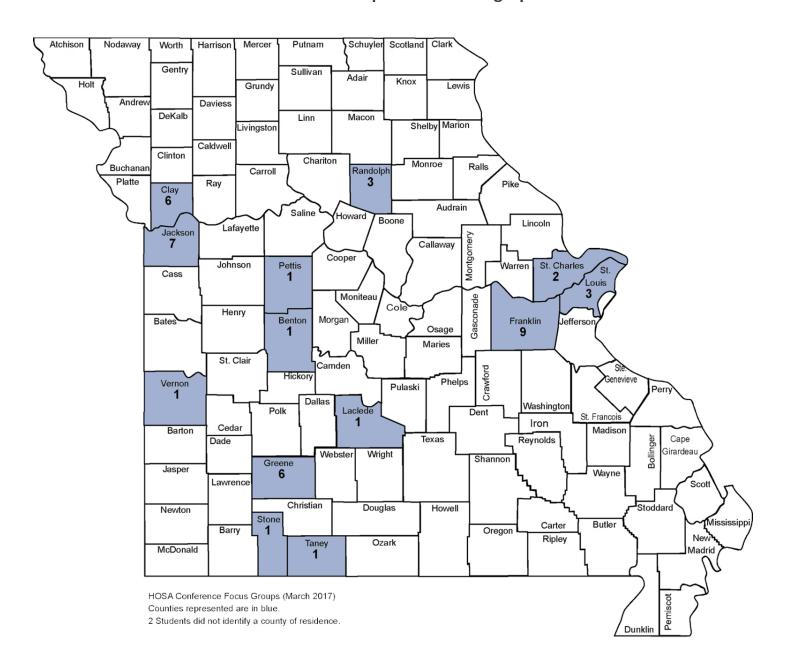
donation prior to obtaining a drivers permit/license. The project team should also consider collecting additional student opinions and thoughtfully and carefully consider each suggestion/response provided prior to the development phase. Information gathered to date should be very helpful and serve as a first step in understanding how to expand and implement the LifeSaversTM Program in high schools throughout Missouri.

LifeSavers™ Program Expansion Project March 2017 HOSA Student Focus Groups Demographics





LifeSavers™ Program Expansion Project March 2017 HOSA Focus Groups Student Geographic Distribution



LifeSavers™ Program Expansion Project March 2017 HOSA Student Focus Groups Feedback

Highlighted are statements of interest and should help guide material development.

Foci	us Group 1	Focus Group 2	Focus Group 3	Focus Group 4	Focus Group 5	Focus Group 6	Focus Group 7
1.	What have you l	heard about organ, e	ye and tissue donation	?			
•	People don't like to donate eyes Don't like to donate face Have to be brain dead to donate	 Icon on driver's license Didn't like hearing about it at DMV for the first time 	 Don't have to donate all, can choose what is donated Long process to get organs (wait list) 	 Important; time is crucial Learned from "Grey's Anatomy" More than 40 parts can be 	 Had people come to school (GOL) Nothing at school Marked on license 	 Driver's license Parents are both nurses and talked about it at home Asked at the DMV 	 Motorcycles are called organ donors/organs on wheels Invaluable to donate; need is high, supply is low
•	Issues with cardiac vs. brain death Lawsuits Meet donor families		 More willing to donate organs than tissue Family decides if you haven't specified a choice 	 donated Some religions think it's wrong Doctors won't try to save you DMV clerk 	Opt in, not opt out; foreign countries have to choose not to be a donor, U.S. you have to sign	Science class	 Business of organ donation hurts third world countries (black market) Misinformed about risk associated with
•	Parents don't want kids to be donors; worried recovery takes place prior to actual death Whole body can be donated for		Family can decide even if you said you wanted to donate	 applied pressure to say "yes" Long waiting lists Possibility of rejection Peer pressure to say "no" 	up; opt out saves more lives Annual Green Out Game (Zac's Challenge); signed up over 1,000 over 1.5 years		 organ donation Pressured to be a donor or not be a donor Kidney donors - lessens life expectancy Never heard
	education				Get in an accident to donate, can't be too hurt		anything about eye donationFiguring out how to use other things for
		ent groups are intere			 Living donation; portion of liver, bone marrow, plasma (learned from Aunt and movie) 		skin (i.e., fish scale which reduces infection risks) • Rejection methods

provided by these students are accurate; and indicate they are knowledgeable about organ, eye and tissue donation, there still appears to be some myths that need to be addressed. One such example is "Doctor's won't try to save you" and "have to get in an accident to donate" are two examples. While students are looking to be the future health care leaders, they still express concerns about peer, parent, and community pressure to either be or not be a donor. Consideration should be given to surveying the general student population vs. students that are in HOSA in order to get a more global understanding of what the average Missouri high school student knows or does not know about organ, eye and tissue donation.

2. Have you or your family been directly affected by donation?

			, ,,			
•	 Aunt had liver transplant 	 Aunt was on waiting list and 	 Best friend's cousin was a 	 Grandfather received tissue 	Yes, Aunt has one kidney	 Dad was born with one kidney, was on
•	• Grandma donated body for Alzheimer's	died while waiting (approximately	donor	Brother's friend - bone marrow	Blood donation because of an accident	the waiting list and was removed because of gout
	research	five years ago)			 Uncle was a donor Friend's brother - bone marrow 	 Brother had muscles transplanted from back to abs
					Two kids at school	

Summary:

When the students were asked this question, all of the focus groups, albeit one, had at least one member of the group directly affected by donation or knew of someone that was affected by donation. The experiences shared were a combination of stories with good and bad outcomes. If they did not have an experience, the students were silent. Most of the experiences shared were positive, though some experienced tragedy. Again, consideration should be given to surveying the general student population vs. students that are in HOSA in order to get a more overall understanding of what the average Missouri high school student has experienced as it relates to organ, eye and tissue donation.

3. What do you know about organ, eye and tissue donation?

	TTTTGT GO YOU INT		about organi, cyc	0									
•	Donate certain organs	•	Long waiting list Have questions	•	Can opt out, not required	•	Living donor's donations	•	Have to be brain dead to donate	•	There is a waiting list	•	Donate upon death for majority of
•	Matching requires more		of how the list works	•	Cultural reasons exists for not	•	Large waiting list Certain kind of	•	After a specific age organs are	•	HOSA project regarding long	•	organs Living donation -
•	than blood type Priority list for receiving	•	Work in a timely manner to keep organs healthy		donating (Native Americans)		death for organ donation		not used (grandpa was 80 and didn't take	•	list Learned some from TV		donate kidney and portion of liver Sign up to be organ
•	Someone added to the list every 12 minutes	•	You have to die a certain way - on life support					•	his organs) How healthy organs are	•	Has to be a good match to transplant	•	donor Notify your family Can have an open
•	Body may not accept transplanted	•	Not enough matches Transplant						determines donation			•	casket Sign up when you get your license

organ Meds required after transplant Family donor/match to bypass waiting list (kidney, liver, etc.) outcomes are not always successful Not everyone can be a donor					 Research is growing body parts using an apple Need family permission to donate Heart is the last organ recovered Locate recipients ASAP due to viability
Summary: Most of the statements of donation. Statements of used," and "need family responses. While brain donation options and need students wanted addition expressed the information through HOSA; "have question through HOSA students' expenses." 4. Have you made a decision about organization.	concern are "learned so permission to donate." T eath is the most commo ed to be included during hal information including on needs to be considere estions of how the list w riences by incorporating	me from TV," "have to me from TV," "have to fime did not permit for n way to donate organ the development staged how the [waiting] listed during program development," and "HOSA projections," and "HOSA projections," and tissue	be brain dead to donallow-up questions that as, living donation and ge of the statewide high works. From the respelopment. Two studen ect regarding long list.	ate," "after a specific may have helped clar donation after cardia h school education pr onses, the simplicity i ts identified areas wh "There is an opportu	age, organs are not rify the students' c death are also ogram. Some of the n how the students ere they can learn more nity for DESE to further
5-Yes, on license 6 Yes Chose to donate with thought of something happens-could help someone else Some parents assisted	7 Yes, registered donors	5 out of 5 have made a decision	 4 Yes; one signed up at Zach's Challenge at the age of 13 or 14 1 not yet; would like to sign up and doesn't feel they knows enough about it Signed ID permit and license 	• 4 out of 4 Yes	9 out of 9 Yes
Summary: Most of the students that registered that decision. and document their decision.	It appears that students	who have enough info	nade a decision about ormation about organ,	eye and tissue donat	
 Yes Education 	Already signed up	Might make decision more	• Yes	If we were better informed,	If someone showed a first person story

changes views		difficult with		we could make a		(donor/recipient
• Don't		more education		better/informed		story)
understand how	•	How		choice	•	Education needs to
the process		presentation is	•	Making a choice		start sooner (prior
works, a barrier		made could		of what to		to license); talk with
 Scary topic, 		make a		donate		family before permit
many are		difference	•	If you		(8 th or 9 th grade)
uncomfortable	•	Present <u>all</u> facts		understand the	•	Broader outreach -
with topic of	•	Family would be		power of the gift		some people think
death		affected				organs will be stolen
 More education 	•	How would				(black market)
may make		family feel?			•	Educating people
people more		,				with correct and
fearful						accurate
 Kids are 						information
influenced by						(sooner)
their parent's					•	Get rid of myths
opinion					•	Multiple sources
 Cultural or 					•	People believe what
religious						teacher says
8 8 1 1					•	Validate information
					•	Personal decision -
						influenced by family
						Let kids do research
						themselves
						Pressured by
						parents
					•	Your body, your
						decision
					•	Religious reasons -
						something to work
						with or around

Summary:

When HOSA focus group students were asked if they would consider being a donor if they knew more about it, several key points were made by the students. The high school education project will benefit from the student feedback. Of particular note is how some students feel more education is helpful, while others believe it can instill fear or make the decision making process more difficult. One student brought up pressure from parents. Another mentioned that religion was something to work with or around. Students in these focus groups want the facts so they can decide if they want to donate and what they want to donate. The students were adamant that education needed to begin sooner. Many heads nodded to the affirmative when a student presented this opinion. This is also an opportunity for DESE to incorporate workshops at the annual spring HOSA conference. In particular – allowing students to do research on a specific aspect of organ, eye and tissue donation and then competing in presentations, debate, medical workshops, etc., as indicated by responses to

some of the questions. The high school education project should consider asking students that may not have as much knowledge about organ, eye and tissue donation to assure that a more global understanding of what the average Missouri high school students wants to learn about organ, eye and tissue donation.

6. Do you know how to register to be an organ, eye and tissue donor in Missouri?

· / · · · · · · · · · · · · · · · · · ·		3. , . ,				
 Driver license 	• Can change	Driver license	• DMV	Signed license	• 3 No	• 6 Yes
 Sign license with 	decision on	 iPhone 	 Apple app 	with witness	• 1 Yes (DMV)	• DMV - valid at 18
two witnesses	DMV website		 Red Cross 	 DMV when get 		years of age; have
 Family decides 	(Kim shared)		 Talk to doctor 	license		to have parent
for you	 Rest of the 		 Online 	 Online 		signature if under
 Online 	students had no		• Call number on			18
registration	comment		website			

Summary:

Some of the statements provided by HOSA focus group students are accurate and indicate their knowledge about organ, eye and tissue donation. Statements of concern are "family decides for you," "can change decision on DMV website," "talk to doctor," and "DMV . . . have to have parent signature if under 18." Time did not permit follow-up questions that may have helped clarify the students' responses. Some of the responses are only partially true and are topics that need to be addressed in the materials for the high school education project. The Apple app is for the national registry, RegisterMe.org. Without getting clarification from the HOSA students, more information is needed. The high school education project team should consider asking students that may not have as much knowledge about organ, eye and tissue donation to better understand what the average Missouri high school students knows about registering as organ, eye and tissue donors. Information from this question should be very helpful during the development of the statewide high school education materials and program.

7. Did you learn about organ donation before you received your driver's license? A. If yes, where did you learn about it? B. If no, would receiving information before you obtain your driver's license been helpful?

• 5-Yes		•	9-Yes	•	7-Yes	•	4-Yes	•	4-Yes	•	2-Yes	•	3-Yes
o Dad e	kplained		o DMV		EMT class		Brother's		o GOL		Parents		Father's health
o Mom			 Mom shared 		 Researched on 		friend		presentation		 Science Class 		issues
menti	oned it		her decision		my own-		o "Grey's		Learned @	•	2-No		o HOSA
o News	stories	•	0-No		presentation at		Anatomy"		young age		Need more		o "Grey's Anatomy"
and "d	Grey's				school		 Uncle said 		and school		information		 Documentary
Anato	my"				Project Lead		"yes"		debate -			•	6-No
o Vice P	rincipal				The Way classes	•	1-No		grandpa/				Yes, receiving
was a	donor				 Talked about it, 		o Easier decision		family open to				information
 0-No 					didn't learn		with more		discussions;				before would be
					new		information		interested in				helpful
					information				organ				 Would not have
				•	1-No				donation -				changed my
					Would have				heavily				opinion
					helped to know				involved in				 Would have liked

more		medical		more information
		profession		sooner
		Health class -		o Educate Parents
		freshman year		who may disagree
		○ Zac's		Kids rely on
		Challenge		parents for
		(didn't ask @		information -
		permit/DMV		make decision
		visit)		based on their
	•	0-No		decisions
		0-Yes		

Summary:

Thirty-four of the students in the HOSA focus groups indicate they learned about organ donation before they received their driver license. HOSA students that learned prior to obtaining a license indicated they learned from their parents, their own research, a documentary, or through EMT, Project Lead the Way, and science classes, or a personal connection to organ, eye and tissue donation. Several of the students also indicated they learned from "Grey's Anatomy" which is not always accurate in the portrayal of the process from registering, to donating, to transplantation. Eight students indicated they did not learn about organ, eye and tissue donation prior to obtaining their driver license. These students indicated they wanted more information prior to obtaining a license so that they could have made an informed decision.

It is unclear if the average student, students not pursuing a medical career, would answer the question in the same manner. When one of the students mentioned that parents needed to be educated, several students nodded in the affirmative. The high school education project team should consider asking students that are not pursing a medical field this question to better understand if they want information prior to obtaining a driver license. Information collected from this question should be very helpful during the development of the statewide high school education materials and program.

8. Have you discussed your decision or wishes about organ, eye and tissue donation with your family or loved ones? Why or why not?

• 5-Yes	• 1-Yes	• 4-Yes	• 2-Yes	• 4-Yes	• 2-Yes	• 0-Yes
• 0-No	• 8-No	• 1-No	• 3-No	• 1-No	• 2-No	• 0-No
		 3-No response 				
Why	Why		Why	Why	Why	Why
 So they are 	 Decision after 	Why	 2-car accidents 	 Military family - 	 More informed 	 Talked about talking
aware in the	conversation	 General sense- 	(personal	big part	 Grandma wants 	about it
event of an	with parents	your body, your	experience)	 Signed up @ 	to donate body	 Grandma wanted to
accident		decision	 Sister brought up 	young age	to science	be an organ donor,
 Told mom - so 	Why Not	 Family is all organ 	discussion	Saving lives -		but wanted her to
they (family)	 Don't want to 	donors-donate all	 Medical family 	don't see why	Why Not	say no because she
know wishes	think something	if it will help	(assumed)	you wouldn't	 Family not in 	didn't want me to
 Mom talked 	will happen to	someone		want to	health	think about death
after I said "no"	them	 In case something 	Why Not	• If gone, what's	care/health field	 They need to know

•	on permit Don't want it to	•	Doesn't come up in normal		happened, they'd (Family) know	•	Subject never came up		the point of keeping them	•	I may not die	•	what you want Disagree (with
	be a surprise		conversation	•	Not in-depth	•	Knew how family	•	Don't have a				parents), but
W	hy Not			•	Tissues and eyes freaked parents		felt		use for them anymore				respect their decision
•	No response				out				,			•	Don't like the
	required			•	Family thought it weird I wanted to donate more than organs			•	ny Not Hasn't come up - hasn't impacted family, not				thought of taking them (loved one) apart - emotional aspect
					organis				taboo			•	Mom answered for
				Wh	ny Not			•	Cultural reasons				her (same decision,
				•	Knew it would start a fight (Family)								but unhappy mom made the decision for her) Family talked about
													it prior to decision
												Wł	ny Not
					students in the HO							•	No response

Summary:

Eighteen, or nearly half of the students in the HOSA focus groups, indicate they have discussed their wishes about organ, eye and tissue donation with their family or a loved one. These students wanted family to know in the event of an accident, so that it would not be a surprise, because tissues and eyes "freaked" parents, personal experience, and personal beliefs. The other half of the students either did not respond or have not discussed the subject because: 1) they don't want to think about something happening to them; 2) not part of normal [family] conversation; 3) it would unsettle the family; 4) cultural reasons; 5) emotional; and 6) family is not in the health care field. One student indicated their family talked about talking about it and the conversation hasn't happened; another disagreed with their parents, but respected their decision; and one was upset that the parent made the decision for them.

This is an opportunity for the high school education project team to incorporate how to discuss the topic of organ, eye and tissue donation in a non-threating way. While it appears the response is more reflective of the average student that is not going into a medical field, following up with said students should be considered. By doing so, the project team can better address family conversations about organ, eye and tissue donation, to be a donor or not, and to register or not register that decision.

9. Are you aware that you can register as an organ, eye and tissue donor in Missouri? • 0-Yes • 0-No • 0-No

Summary:

All but nine students indicated they were aware they could register as an organ, eye and tissue donor in the State of Missouri, yet many of these same students are registered donors. It is unknown if the students did not understand the question and/or if the overall response

from all of the HOSA focus group students is reflective of the average student not interested in a health related field. Obtaining the opinions of students not pursuing a career in health care should be considered in order to determine if the various means available to register in the State of Missouri should be incorporated into materials developed for the statewide high school education program.

10. In which class would you want to discuss organ, eye and tissue donation? If not in the classroom, where? Youth organization or group? Health Freshman health Freshman No response Anatomy Any health Science classes Health (9th Health based class class (required) -Biology Assembly/with Not classroomfour students Science grade) x 5 votes Health speaker Health Science where: (connected to agreed with this Any Freshman More than one occupation SAAD Not classroom -English - the way the topic) statement class class where 2 students Freshman class HOSA Should cover teachers talk Middle School suggested biology because that's HOSA group in about things assembly Speaker during donation when get lunch school present to discussion based Parent/Student and anatomy information and 2 students permit-all whole school class: can talk assembly how to register Motivational freely and suggested English agreed Not a youth Important to do in openly students are classroom to speakers in group assembly • Health - just comfortable with reach everyone Better in school conversations in the **HOSA** during another topic -(students) English classroom; blood drives not passionate Not classroom-Not classroom-where: **Guest Speaker** they could read where about it and have an Social studies • No response Fire station-guest open conversation Contemporary speaker If taught in health Community Issues class, curriculum Centers Global Issues would need to be Doesn't go with Psychology standardized church (touchy Sociology 2 students subject) Anatomy suggested Maybe if someone **World Religions** Government class in church is since a driver's connected to Not classroom license is considered donation okay where civic duty @ DMV Depends on HOSA Teacher needs to be Church conference unbiased Sporting events -(health care example Zach's professional Not classroom-where Challenge students) No response football green out Non-health care challenge students may not have as much interest School best

								•	Strong social				
									media				
									(Facebook)				
								•	Videos				
								•	PSAs				
								•	Similar to				
									MoDot/Anti-				
									Smoking (Truth)				
Su	mmary: The I	HOS	A students partic	ipati	ng in the focus grou	ıps 1	thought broadly ar	nd o	utside-of-the-box	whe	en answering this o	ques	tion. Multiple ideas
	-				uld be considered b								-
			•		ty to sign driver lice		-						·
	•	-	•		d should be conside				. ,		0,1		'
	•						, , ,				,		0 0 1
					•						•		lents outside of the
					ed community cent	-			•		•		
	prov	ide	the project team	ı wit	h a lot of avenues i	n wl	nich to assure stud	ents	are educated abo	out (organ, eye and tiss	sue o	donation.
11	. If information w	as	oresented in a cla	ssro	om, how do you we	ant	to receive the info	rma	tion? (Notes for fo	acili	tator: video, gues	t sp	eaker, online, etc.)
•	Voluntary vs.	•	Health class	•	Guest speaker	•	Someone with	•	Visual	•	Stories	•	3 students indicated
	required	•	Biology		(don't get them		personal	•	Guest Speaker -	•	Guest Speaker		presentation
•	May not have	•	Bio-Med		often-more		experience		helps students	•	"Bring the real		video/visuals and
	participation if	•	A & P		interesting)	•	No video unless		relate		life stuff"		discussion
	not required	•	Human	•	Bored with online		is a personal	•	Depends -	•	Plant seed with	•	Little bit of e/t
•	Guest speaker-		Physiology	•	Video-lights off,		experience		should be		an assembly and	•	Unbiased
	affected by		, 0,		heads down	•	Guest speaker		interactive		follow-up in a	•	First person stories
	donation			•	Guest speaker		·	•	Stats - how it		class	•	Guest speaker
•	Cover the basics				w/goodies/s/t of				helps others			•	In-class debate
•	Go over forms				interest			•	Flyer/brochure				
•	Keep it light			•	Stickers - s/t to				at end - have				
•	No formal				take home and				students and				
	decision				share with family				teachers to				
	required			•	Information to				share with				
•	Handout to				take home to				others				
	make parents				parents - may			•	Simulated car				
	aware				make them more				crash - show				
	(permission slip)				accepting				process of organ				
•	Video/story			•	Relate to a				donation after				
•	How transplant				recipient rather				accident (walk				
	process works				than public health				through) -				
•	Videos with				educator				graphic for				
	both sides			•	Both a recipient				health				
	2011 01460				and public health				occupation				

educator - more	students, less	
impact	graphic for	
	others (no	
	bodies)	
	 Process so we 	
	see what we are	
	signing up for	
	 Cartoons (1 yes, 	
	1 no)	
		impact graphic for others (no bodies) Process so we see what we are signing up for Cartoons (1 yes,

Summary:

If information about organ, eye and tissue donation is presented in the classroom, students have provided plenty of insight about what they want. It is unknown if their opinion, as future health care individuals, is reflective of the average student. The project team should consider collecting additional student opinions and consider each of the suggestions/responses carefully before the development phase of the statewide high school education program.

12. How would you like information about organ, eye and tissue donation presented?

- a. Peers
- b. Teacher
- c. Rally/guest speaker
- d. Student reporter/video
- e. Assembly/guest speakers
- f. Town Hall format

• Peers - 5	Peers - 0	• Peers - 1	• Peers - 0	• Peers - 1	Peers - 1	 Ran out of time for
• Teacher - 0	• Teacher - 0	• Teacher - 1	• Teacher - 1	• Teacher - 0	Teacher - 1	this question.
• Rally/Speaker -	• Rally/Speaker -	 Rally/Speaker - 0 	• Rally/Speaker - 1	Rally/Speaker - 1	 Rally/Speaker - 4 	
5	7	• Student Reporter -	• Student Reporter	• Student	 Student 	• Peers - 0
 Student 	 Student 	0	- 0	Reporter - 0	Reporter - 0	• Teacher - 0
Reporter - 0	Reporter - 0	Assembly - 1	 Assembly - 1 	 Assembly - 3 	 Assembly - 4 	 Rally/Speaker - 0
 Assembly - 0 	 Assembly - 0 	• Town Hall - 1	• Town Hall - 0	Town Hall - 0	 Town Hall - 0 	• Student Reporter - 0
• Town Hall - 0	• Town Hall - 1	• Other (List) - 0	• Other (List) - 4 -	• Other (List) - 0 -	Other (List) - 0	 Assembly - 0
• Other (List) - 0	• Other (List) - 1		all said personal			• Town Hall - 0
	o Video	 Peers and teacher 	experience	Hank's Hope	 If peers are 	Other (List) - 0
Students noted that		combo - need to		assembly	informed/	
a combination of	Student noted that	have credibility		w/video	students may	
peers and guest	rally speaker needs	(may not believe		 Assembly may 	ask more	
speaker	to be a guest with a	another student)		be blown off by	questions	
	personal story	 Green Out - Zac's 		some students	 Town Hall would 	
		Challenge -		(easy at some	not reach as	
		Assembly w/Zac's		schools)	many	
		parents		 Not peers 		
		 Setting where 		 Rally may get 		

	people can ask		kids too excited		
	questions		- not a rally topic		
	 Smaller groups; 		 Peers and rally 		
	interactive; not		would be best -		
	someone just		learn from each		
	talking		other		
	 People can skip 		 Rally may make 		
	assemblies		topic more		
	 Can't ask 		comfortable;		
	questions at		assembly too		
	assembly		serious		
Summary: Students were all over the			nted information abou	it organ, eye and tissu	e donation presented.
The most popular options					
	Style	e:			
	Rally/Sp	eaker			
Rally/Spe	aker 18 18				
	Style				
	Othe				
Assembly					
Peers	8				
Other	4				
Teacher	3				
Town Hal	1 2				
Students provided pros ar	d cons for some of the	options discussed. Wh	nile the traditional way	y of teaching the LifeSa	avers [™] Program is the
most popular response wi	th 18 students; a total o	of 26 responses includ	ed other methods. Du	e to the varied respon	se, the project team
should consider a compre		•		· ·	
opportunity to participate					
13. What information or factors would help you decide to be a donor?					
Knowing the Maybe some	 Personal story of 	Very touching	 Stories of 	No responses	Ran out of time for
process information on	donation (who	story	donors		this question.
(donation) why people	was helped)	 Personal story 	 Knowing saving 		
• Process choose not to	 General 	 Decision as to 	lives -		
(transplant) donate	explanation	what organs to	connecting		
Knowing could	 Concern about 	donate	donor with		
save many lives	funeral (provide	 Statistics - need 	recipients		
 Benefiting 	clarification)	for donation	 Project Lead the 		

someone's life -	More information Knowing how to Way (PLTW) -
has purpose	on how it save someone cadaver lab -
 Grateful 	helps/benefits • No pressure - no explain what
recipients/	others - more decision is wrong organs can be
families	incentive to used and what
Knowing people	donate can't
die waiting	Have class with Autopsy project
	students prior to (PLTW) used
	permit/driver face time to
	license walk through
	 Middle school the process
	would be a • Do not use the
	good place to term harvest
	start
	o Give some
	information at
	this point,
	maybe not all of
	the details -
	series of
	conversations
	o Important to
	bring up at this
	age - bad things
	happen at any
	time; prepare
	them on how
	they can help

For the students who had time to answer the question, several suggestions were made about what information/factors should be included as part of the learning process; including personal stories. Students once again stressed that education should start sooner than the ninth grade. The project team should consider collecting additional student opinions and consider each of the suggestions/responses carefully

before the development phase of the statewide high school education program.

Summary:

Missouri HOSA ATTN: Shelly Wehmeyer, 5th Floor P.O. Box 480 Jefferson City, MO 65102



Dear HOSA Local Chapter Advisor,

Missouri HOSA is collaborating with the Missouri Department of Health and Senior Services and their partners to collect self-reported organ, eye and tissue donor related information about attitudes, beliefs and educational learning styles from high school students. Data collected will aid in the development of resources and an education program for high school students about organ, eye and tissue donation and Missouri's associated registry.

High school student focus groups will be conducted at the Missouri HOSA State Leadership Conference on March 27-28, 2017 during Education Symposium sessions. **No identifying information will be collected**. Diverse opinions from male and female students from around the state are needed. There is time for up to 105 freshmen to senior Missouri HOSA student members to participate. All participants must have a signed release, which is attached to this letter. Participation is voluntary.

We are asking for your support and assistance by recommending and encouraging at least one student in your chapter to consider participation. Enclosed is the permission letter for you to distribute to the student members in your local HOSA chapter. Please direct any questions to Shelly Wehmeyer at (573) 751-3407 or Shelly.Wehmeyer@dese.mo.gov.

Warm regards,

Missouri HOSA

1200 SE Adams Dairy Parkway Blue Springs Missouri 64014



Dear Parent/ Guardian,

HOSA is collaborating with the Department of Health and Senior Services and their partners to collect self-reported organ, eye and tissue donor related information about attitudes, beliefs and educational learning styles from high school students. Data collected will aid in the development of resources and an education program for high school students about organ, eye and tissue donation and Missouri's associated registry.

High school student focus groups will be at the HOSA Conference, March 28-29, 2016. Your child has the option to participate. No identifying information will be collected. Participation is voluntary and requires the following release. If you approve of your child participating in a focus group, please complete and return this document no later than March ___, 2016.

Ι,	(printed name of legal g	uardian), give my child,
	(printed name of child)	permission to participate
in a survey/focus group in coordination wi	th the Missouri Department	t of Health and Senior
Services and its partnering organization re	egarding organ, eye and tis	sue donation education.
		
		Legal Guardian Signature

Warm regards,
Missouri HOSA

Organ and Tissue Donation Education Initiative for High School Youth

Facilitator Instructions - HOSA Conference March 2017

Prepare yourself. Being prepared improves confidence and makes the focus group more enjoyable for the participants. Do you have all of your supplies?

Be sure that each focus group is manageable, and does not have more than 15 students per focus group. **Limit** the focus group **time to 45 minutes**. This will give you time to collect documents and for the next facilitator to set up.

Start and stop promptly as scheduled. Students have other events/activities in which they are participating during the HOSA Conference.

Be clear at the start that you want and welcome everyone's participation as it is important that all voices are heard. The focus group is a closed session for those students who signed up and provided signed permission letters.

- Use a hand gesture you are comfortable with and is not offensive to queue students to speak. You can even say, something like, "Let's start with you and then go around the room" Make it possible for students to pass and say nothing if they do not want to.
- **Be patient and silent** after asking. Some individuals need time to think about the questions and provide a response
- Review posted rules.

Pass around the attached **demographic information form** and ask each student to complete one line. Students are not to put their name on the demographic information form. Verify that all students have completed the form.

While students are completing the form, **inform the students about the focus group** and that you are going to ask a series of question about organ, eye and tissue donation being taught in the classroom. You will also be asking them questions about their knowledge and beliefs about organ, eye and tissue donation.

An assistant will capture the main thoughts and ideas presented by students on the flip chart.

After the focus group, return your packet and student responses to the Organ and Tissue Donor Exhibit booth. Hand the materials to Valerie Volkart, Virginia Beatty or Sandy Simaitis.

Organ and Tissue Donation Education Initiative for High School Youth

High School Student Focus Group Questions - HOSA Conference - March 2017

Primary Focus Group Questions:

- 1. What have you heard about organ, eye and tissue donation?
- 2. Have you or your family been directly affected by donation?
- 3. What do you know about organ, eye and tissue donation?
- 4. Have you made a decision about organ, eye and tissue donation?
- 5. Would you consider being a donor if you knew more about it?
- 6. Do you know how to register to be an organ, eye and tissue donor in Missouri?
- 7. Did you learn about organ donation before you received your driver's license?
 - a. If yes, where did you learn about it?
 - b. If no, would receiving information before your obtain your driver's license been helpful?
- 8. Have you discussed your decision or wishes about organ, eye and tissue donation with your family or loved ones?
 - a. Why or why not?
- 9. Are you aware that you can register as an organ, eye and tissue donor in Missouri?
- 10. In which class would you want to discuss organ, eye and tissue donation?
 - a. If not in the classroom, where? Youth organization or group?
- 11. If information was presented in a classroom, how do you want to receive the information? (Notes for facilitator: video, guest speaker, online, etc.)
- 12. How would you like information about organ, eye and tissue donation presented?
 - a. From Peers (teen to teen)
 - b. Teacher presents the information
 - c. Rally with guest speakers
 - d. Student Reporter video
 - e. Assembly with guest speakers
 - f. Town Hall format with students asking questions of specialists? (Organ and tissue donor recovery agencies, registry staff, individuals affected by organ, eye and tissue donation, transplant surgeon, etc.)
- 13. What information or factors would help you decide to be a donor?

Focus	Group #	F	G	í

Date

3/27/17

Pages 1-3

Organ and Tissue Donation Education Initiative for High School Youth Demographic information of focus group:

	Age (15, 16, etc.)	Choose Gender	Choose Race	Choose Grade	School Type	County of Residence
Student 1	☐ 14 ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19	Female Male Refuse to provide	White Black or African American American Indian or Alaska Native Asian Native Hawaiian or Other Pacific Islander Refuse to provide	9th 10th 11 th 12 th	☐ Public☐ Private	
Student 2	☐ 14 ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19	Female Male Refuse to provide	White Black or African American American Indian or Alaska Native Asian Native Hawaiian or Other Pacific Islander Refuse to provide	9th 10th 11 th 12 th	Public Private	
Student 3	☐ 14 ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19	Female Male Refuse to provide		9th 10th 11 th 12 th	Public Private	
Student 4	☐ 14 ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19	Female Male Refuse to provide	White Black or African American American Indian or Alaska Native Asian Native Hawaiian or Other Pacific Islander Refuse to provide	9th 10th 11 th 12 th	Public Private	
Student 5	☐ 14 ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19	Female Male Refuse to provide		9th 10th 11 th 12 th	Public Private	
Student 6	☐ 14 ☐ 15 ☐ 16	Female Male Refuse to provide	☐ White ☐ Black or African American	9th 10th 11 th	Public Private	

	☐ 17 ☐ 18 ☐ 19		American Indian or Alaska Native Asian Native Hawaiian or Other Pacific Islander Refuse to provide	12 th		
Student 7	☐ 14 ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19	Female Male Refuse to provide		9th 10th 11 th 12 th	Public Private	
Student 8	☐ 14 ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19	Female Male Refuse to provide	White Black or African American American Indian or Alaska Native Asian Native Hawaiian or Other Pacific Islander Refuse to provide	9th 10th 11 th 12 th	Public Private	
Student 9	☐ 14 ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19	Female Male Refuse to provide		9th 10th 11 th 12 th	Public Private	
Student 10	☐ 14 ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19	Female Male Refuse to provide		9th 10th 11 th 12 th	☐ Public ☐ Private	
Student 11	☐ 14 ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19	Female Male Refuse to provide		9th 10th 11 th 12 th	Public Private	

12	☐ 14 ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19	Male Refuse to provide	Mhite Black or African American American Indian or Alaska Native Asian Native Hawaiian or Other Pacific Islander Refuse to provide	9th 10th 11 th 12 th	Public Private	
Student 13	☐ 14 ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19	Female Male Refuse to provide	White Black or African American American Indian or Alaska Native Asian Native Hawaiian or Other Pacific Islander Refuse to provide	9th 10th 11 th 12 th	Public Private	
Student 14	☐ 14 ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19	Female Male Refuse to provide	White Black or African American American Indian or Alaska Native Asian Native Hawaiian or Other Pacific Islander Refuse to provide	9th 10th 11 th 12 th	☐ Public☐ Private	
Student 15	☐ 14 ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19	Female Male Refuse to provide	White Black or African American American Indian or Alaska Native Asian Native Hawaiian or Other Pacific Islander Refuse to provide	9th 10th 11 th 12 th	Public Private	



Organ and Tissue Donation Education Initiative for High School Youth

A collaborative effort of the Gift of Life, Missouri Department of Health and Senior Services, Department of Elementary and Secondary Education, Mid-America Transplant and the Governor's Organ Donation Advisory Committee.

Data and information in this report may be used only for public health practice. Direct questions to:

Missouri Department of Health and Senior Services

Organ and Tissue Donor Program

P.O. Box 570

Jefferson City, MO 65102-0570

organdonor@health.mo.gov,

573.522.2847 or toll free 888-497-4564

Health.mo.gov/organdonor

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