



Rare Disease Day Display



Purpose: To encourage Health Science students to improve their ability to present themselves, communicate rare disease information, and propose a cure/treatment or way to improve a quality of life issue.

Description: Teams consisting of two (2) competitors shall develop a visual display describing a specific rare disease as well as a proposed cure/treatment or way to improve a quality of life issue related to the rare disease. The display allows the students to express ideas through an artistic medium to highlight what they have learned about a particular rare disease through research, interactions with a patient and their family, and interactions with a researcher, clinician and/or other healthcare professional.

The students will also be judged on their ability to present themselves and communicate the rare disease information to others, as well as propose a cure/treatment or way to improve a quality of life issue. Additionally, students will present their fundraising efforts.

The goal of this competitive event is to support policies and practices that:

1. facilitate research;
2. encourage development of innovative treatments;
3. advance awareness and understanding of rare diseases;
4. ensure patient access to care;
5. help break the isolation of the people living with rare diseases; and
6. provide opportunities for students to develop, practice, and refine their leadership and teamwork skills to achieve a seamless transition from education to a career.

EVENT GUIDELINES

- Dress Code:** Competitors must be in official HOSA uniform. HOSA Uniform Policy:
- Tailored navy blazer with emblem affixed over the heart
 - Shirt/blouse for females (white tailored or short-sleeve white jewel neck shell)
 - Shirt for males—white closed-neck, man-tailored dress shirt, suitable for use with a tie
 - Accent for female members - maroon HOSA scarf or tie is optional
 - Accent for male officers - navy or maroon long tie
 - Matching navy slacks for males and matching navy slacks for females. No skirts.
 - Closed-toe blue or black shoes (hose optional)

- Rules and Procedures:**
1. Competitors in this event must be active members of HOSA-Future Health Professionals, in good standing in the category in which they are registered to compete.
 2. Competitors must be familiar with and adhere to the "[General Rules and Regulations of the National HOSA Competitive Events Program](#) (GRR)."
 3. The display must be presented by a team of two. Only one rare disease may be presented, and student must choose a different rare disease each year if competing consecutively.
 4. Conference calls, Skype, or videoconferencing are recommended for interviews with the patient/family, researcher, clinician, and/or other healthcare provider. Travel to conduct interviews during the school day is not recommended.
 5. Tools to assist in conducting interviews with practitioners and family have been developed. It is recommended that advisors work with students to prepare for interviews using the interview tools. Students should attempt to have both team members present for each interview.
 6. Students participating in Rare Disease Day Display will choose a different rare disease/condition to research and present each year.
 7. Teams are expected to share stories, examples, and experiences that illustrate the interactions with the patient, family, researcher, clinician, and/or other healthcare professionals. However, **the health information of the patient is protected and names or identities should not be revealed in the display or presentation.**

Rare Disease Display:

The display is as integral part of the event presentation, but can also stand alone as an effective illustration of the chosen rare disease as well as cure/treatment or way to improve a quality of life issue. All displays will have a consistent framework, and teams will be judged on how effectively the display informs about the rare disease, AND supports the verbal presentation.

1. The work **must** be the work of the competitors, including the artistic aspects of the display. Allowable artwork may include:
 - Competitor produced illustrations, designs, and/or computer-generated graphics.
 - Clip art or other graphics used in compliance with copyright laws.
 - Photographs used with permission or in compliance with copyright laws.
 - Computer or machine generated lettering.

2. The display uses a single wall tri-fold presentation display board that is 48" x 36" unfolded, in any color, made of foam or corrugated.
3. The competitor is responsible for the safety and proper functioning of all equipment they bring to this event. The competitor *may not* use any flames, body fluids, living organisms, sharps, or potentially hazardous equipment/materials. Invasive procedures and skin puncturing are **prohibited**. This is repeated – see #6
4. The table-top display must be able to stand on a standard conference table furnished on site. If 8 ft. tables or banquet rounds are used, there will be two displays per table. Presentation display boards that are 48" x 36" are REQUIRED. In addition to the presentation board, the display may include models, mannequins, pamphlets, brochures, or any other method or combination of physical objects or props to display the project. Computers and electronics may NOT be used.
5. DISPLAY MEASUREMENTS:

Once positioned on the table with three-dimensional display items, the maximum dimensions are:

HEIGHT: 36 inches WIDTH: 48inches DEPTH: 24 inches

The display will be measured by the Section Leader or Event Manager before judging begins, from a beginning point to the furthest point of the display.

- Height will be measured from the table top to the highest point of anything on the display, and must not exceed 3 feet.
 - Width will be measured from the widest point of anything on the display to the opposite point.
 - Depth will be measured from the widest point of anything on the display to the opposite point.
 - Nothing may overlap the sides of the display table, with the exception of the table drape.
 - Dimensions include models, mannequins and all other display items.
 - Information or display items outside the dimensions will not be considered part of the display and subject to point deductions.
6. The fundraising component will take place between **January 2, 2018 and the end of the day on February 23, 2018**. Fundraising efforts will be done electronically through a website set up specifically for the team and the corresponding rare disease. Teams raising the most funds for rare disease research will be recognized at the closing ceremony on Rare Disease Day.
 7. Local advisors will register for a rare disease topic selected from a section in the Professional Development Management System (PDMS) online. Topic/disease selection will be on a first-come, first-serve basis available from **October 2, 2017 through October 13, 2017**. Each team will have a different topic. Once a topic is chosen, advisors and students will automatically be added to the HOSA Conference Management System (CMS) and an invoice will be generated.

PDMS Course #: 25446
CMS Title: Rare Disease Day 2018

8. Students will be recognized at the state level for their participation. A first, second, and third place medallion will be awarded at the closing ceremony on Rare Disease Day. Additionally, students and advisors will be asked to attend the HOSA State Leadership Conference held at the University of Delaware – STAR Campus to be recognized on March 28, 2018. Students will be eligible to compete at the HOSA International Leadership Conference (ILC) in the Outstanding HOSA Achievement event, which is a recognition event (see guidelines at http://www.hosa.org/sites/default/files/17-18OAguidelinesaug31_0.pdf).

The Competitive Process:

1. This event will be judged on **Tuesday, February 28, 2018** at the newly expanded Nemours A.I. duPont Hospital for Children five-story Fusco Atrium. Students will have their projects on display from 9:15 am- 2:00 pm. Presentations to judges will begin at 9:30 am.
2. Each team will be judged on their overall display and how well they documented the rare disease information through the display. Each team will also be judged on their ability to communicate information to the judges about the rare disease, proposed cure/treatment or way to improve a quality of life issue, interaction with a patient and family, interaction with a researcher, clinician and/or other healthcare professional and fundraising successes. Time cards will be shown with one (1) minute remaining and “stop” at the end of the 10 minutes.
3. Note cards are permitted during the oral presentation. Electronic notecards (on a smart phone or tablet) are permitted.
4. Costumes and hand-held props are not permitted during the oral presentation.
5. **USE OF DISPLAY DURING PRESENTATION:** Visuals or display items used during the presentation portion of the event may be touched or picked up **BUT MUST** remain contained within the dimensions of the display. **Items removed from the display will be considered outside the dimensions of the display and subject to point deductions.**
6. No equipment/supplies (except tables) will be provided for this event. All equipment/supplies needed must be provided by the team. It is the team’s responsibility to ensure that all equipment is in working condition.
7. Electricity will not be provided and may not be used.
8. In the event of a tie, a tie-breaker will be determined by the areas on the rating sheet section(s) with the highest point value in descending order.

Activities Timeline:

It will be the responsibility of the HOSA members/competitors and HOSA advisors to follow the project timeline as written below:

EVENT GUIDELINES

Activity	When	Where
Select Rare Disease (PDMS 25446)	10/2/17-10/13/17	School with Advisor
Conduct Research of selected Rare Disease	10/15/17-10/31/17	School and/or Home
Conduct Interviews	11/1/17-12/15/17	School and/or Home
Develop Rare Disease Display	12/18/17-1/31/18	School and/or Home
Conduct Fundraising	1/2/18-2/27/18	School and/or Home
Practice Presentation	2/1/18-2/14/18	School and/or Home
Round 1 Presentation	2/15/18	Dover with Advisor
Edits to Display and Presentation Practice	2/16/18-2/17/18	School and/or Home
Rare Disease Day	2/28/18	Al duPont Hospital for Children

Competitor must provide:




- Display
- Index cards or electronic notecards for presentation (optional)

Event site will provide:

- Plain, white table drape (optional)
- Display table

Facilities, Equipment and Materials (Per Section):

- One table per team (6' tables) or two teams per table (8' tables).or banquet rounds usually placed in one long row per section.
- Two - three chairs per display or table (for competitors while they are waiting to be judged, and for judges during the competitor presentation.)
- Calculators (if needed), clip board and pencils for judges
- Tape measure
- Team numbers for tables
- Rating sheets – one per judge per team
- Evaluation Forms – competitor, judge, and personnel
- #2 lead pencils with eraser to complete evaluations
- Flash card for 1 minute remaining **Icon Key:**

	Team event – Minimum and maximum (if greater than 2) number of team members.
	Plagiarism or copyright violation is prohibited.
	A Showcase will be offered for this event.

RARE DISEASE DISPLAY JUDGE'S RATING SHEET

Team # _____

Judge's Signature _____

Items Evaluated	Points Possible					Points Allocated
	Superior	Excellent	Good	Fair	Poor	
1. Oral Presentation Rare disease information presented in a clear and concise manner. Oral presentation demonstrates insight and a deep understanding of the rare disease. Team members were able to share stories, examples, and experiences that illustrate the interactions with the patient, family, researcher, clinician, and other healthcare professional. A variety of methods were used to complete the rare disease research. Voice (volume/grammar) and enthusiasm. Appearance, poise, eye contact, gestures.	10	8	6	4	2	
	10	8	6	4	2	
	10	8	6	4	2	
	10	8	6	4	2	
	10	8	6	4	2	
	10	8	6	4	2	
2. Display Artistic/design value <i>Creativity and originality</i> Display information was easy to follow, neat, concise and spelled correctly. Display provides an overview with accurate and important information that clearly describes the rare disease as well as a proposed cure/treatment or way to improve a quality of life issue.	10	8	6	4	2	
	10	8	6	4	2	
	10	8	6	4	2	
3. Display space is within listed dimensions All points are awarded for this item if display is within the proper dimensions, and no points if it is not. (H-36", W-48", D-24")	10					
TOTAL POINTS -- Possible/Awarded	100	72	54	36	18	

Appendix A

Rare Disease Day 2018

PARENT INTERVIEW QUESTIONS

Instructions: These guidelines are to provide HOSA members with suggestions for questions that may be helpful in conducting the Parent Interview for the Rare Disease Day Display competitive event. This is not an exhaustive list; therefore, you may add questions about areas of the child, family, or rare disease that interest you and/or relate to your career pathway. As you interview, focus on the answers that the parents are providing, since that may lead to additional relevant questions. Try to find a way for both team members to interview the parent(s) either by using a speaker phone or initiating a 3-way or 4-way conference call.

Introduction

Hi! Our names are _____. We attend _____ and are studying _____.

(Your Names) (Name of School) (Health Science Program)

We are participating in the Rare Disease Day at Nemours A.I. duPont Hospital for Children as part of our student organization called HOSA-Future Health Professionals. We were wondering if we could ask you a few questions about _____ and _____.

(Child's Name) (Disease/Condition)

Thank you.

Interview Questions

1. Tell me about _____.
(Child's Name)
2. When was _____ diagnosed?
(Child's Name)
3. What is a typical day like for _____? What is the most challenging part of your day?
(Child's Name)
4. How many doctors does _____ see?
(Child's Name)
5. How often does _____ get admitted to the hospital?
(Child's Name)

6. What is _____'s schedule for medications and treatments each day?
(Child's Name)
7. Do you use any medical equipment? If so, what is it and what is it for?
8. How does the condition affect _____'s activities of daily living (ADLs)?
(Child's Name)
9. Does _____ go to school? If so, what grade are they in? What kind of classroom do they attend?
(Child's Name)
10. Does _____ have any therapies at school or home (such as physical therapy, occupational therapy or speech/language therapy)?
11. How does _____'s condition affect him/her cognitively (process of learning)?
(Child's Name)
12. What does _____ like to do for fun?
(Child's Name)
13. What are your concerns about _____'s future?
(Child's Name)
14. Is there one thing that could make _____'s life easier/better?
(Child's Name)
15. What have you learned from being a parent of a child with this disease/condition?
16. Is there anything else you think we need to know or that you would like to share about _____?
(Child's Name)

We really appreciate your time. We have been given the opportunity to present at Rare Disease Day on 2/28/17 at Nemours A.I. duPont Hospital for Children between 9:30 am and 2:00 pm. We were wondering if there is a chance that you will be able to attend, and if we will have the opportunity to meet you and _____ on that day.
(Child's Name)

Judging will take place between 9:30 am and 11:30 am, but we will otherwise be available to meet you.

Thank you again for your time and willingness to participate in this event with us. It has been a great learning opportunity.

Appendix B

Rare Disease Day 2018

RESEARCHER/CLINICIAN INTERVIEW QUESTIONS

Instructions: These guidelines are to provide the HOSA members with suggestions for questions that may be helpful in conducting the Research/Clinician Interview. This is not an exhaustive list; therefore, you may add questions about the rare disease and research that interest you and/or related to your career pathway. As you interview, focus on the answers that the professional(s) are providing, since that may lead to additional relevant questions. Try to find a way for both team members to interview the professional(s) either by using a speaker phone or initiating a 3-way or 4-way conference call.

Introduction

Hi! Our names are _____. We attend _____ and are studying _____.
(Your Names) (Name of School) (Health Science Program)

We are participating in the Rare Disease Day at Nemours A.I. duPont Hospital for Children as part of our student organization called HOSA-Future Health Professionals. We are wondering if we could ask you a few questions.

Thank you.

Interview Questions

17. How do patients get _____?
(Name of Disease/Condition)
18. Will other family members get _____?
(Name of Disease/Condition)
19. What type of research or therapy is currently being done on _____?
(Name of Disease/Condition)
20. Do you receive funding and where do you receive funding from to conduct your research work on this disease/condition?
21. Are there many researchers investigating this disease/condition?
22. Do the researchers work closely with families and clinicians?

23. Do you use any medical equipment? If so, what is it and what is it for?
24. Translational research (from research bench to bedside and back - clinic to community), what does that mean and how can that help?
25. Are you working with any new drugs/clinical trials to see what might help this disease/condition?
26. Does the treatment for this disease/condition hurt the patient?
27. Do patients have to stay in the hospital for a long time?
28. How many patients are there with this type of disease/condition? How many patients are seen at Nemours?
29. What is the future direction of research for this disease/condition?
30. Do you think we can find a cure for _____?
(Name of Disease/Condition)

We really appreciate your time. We have been given the opportunity to present at Rare Disease Day on 2/28/17 at Nemours A.I. duPont Hospital for Children between 9:30 am and 1:30 pm. We were wondering if there is a chance that you will be able to attend, and if we will have the opportunity to meet you on that day.

Judging will take place between 9:30 am and 11:30 am, but we will otherwise be available to meet you.

Thank you again for your time and willingness to participate in this event with us. It has been a great learning opportunity.