



Rare Disease Day®



## Rare Disease Day Display



**Purpose:** To encourage Health Science students to improve their ability to present themselves, research, and 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 a visual and verbal presentation that highlights 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. 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 (HIPAA).**

### 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 the audience 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.

## EVENT GUIDELINES

2. The display uses a single 48”X36” poster, which is not mounted on a foam board. Posters will be printed for the teams. **Submission deadline is February 14, 2019 at 6pm.**
3. 48”X36” posters will be displayed in a designated area prior to the competitors’ arrival. In addition to the academic poster, the display may include models, pamphlets, brochures, or any other method or combination of physical objects or props that presenters bring to the presentation to judges. Computers and electronics may NOT be used. Please note: space is limited.
4. The fundraising component will take place between **Wednesday, January 2, 2019 and 6pm on Friday, February 22, 2019.** Fundraising efforts will be done electronically through a website set up specifically for the team and the corresponding rare disease. Competitors should use the link to the fundraising page to promote their fundraising effort on social media or email. Teams raising the most funds for rare disease research will be recognized at the closing ceremony on Rare Disease Day.
5. 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 **Monday, October 1, 2018 through Friday, October 12, 2018.** Each team will have a different topic, and returning competitors are required to select a different selection than previously presented. 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 2019**

6. 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 April 4, 2019. 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](http://www.hosa.org/sites/default/files/17-18OAguidelinesaug31_0.pdf)).

### **The Competitive Process:**

1. This event will be judged on **Thursday, February 28, 2019** at the newly expanded A.I. duPont Hospital for Children five-story Nemours Pavillion. 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.

## EVENT GUIDELINES

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. Except for poster printing, no equipment/supplies will be provided for this event. All equipment/supplies needed must be provided by the team.
6. Electricity will not be provided and may not be used.
7. 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:

Activity	When	Where
Select Rare Disease (PDMS 25446)	10/1/18-10/12/18	School with Advisor
Conduct research of selected Rare Disease	10/15/18-10/31/18	School and/or Home
*Conduct interviews	11/1/18-12/14/18	School and/or Home
Develop Rare Disease display	12/18/17-1/31/19	School and/or Home
Conduct fundraising	1/2/19-2/22/19	School and/or Home
Final poster edits to advisor	2/5/19	School and/or Home
Advisor approves poster upload to STEM Premier	2/5/19	School
Upload poster deadline	2/14/19	School or Home
Practice presentation	2/6/19-2/11/19	School and/or Home
Submit RRD round 1 video to STEM Premier	2/12/19	School or Home
Virtual round 1 review and feedback	2/13/19-2/14/19	
Final edits to presentation	2/14/19-2/27/19	School and/or Home
Rare Disease Day 2019	2/28/19	AIDHC

\*Phone interviews must be conducted by 12/14/18 prior to researchers and clinicians holiday travel.

#### Competitor must provide:

- Index cards or electronic notecards for presentation (optional)

#### Event site will provide:

- Academic poster printing
- Display space



**Facilities, Equipment and Materials (Per Section):**

- Calculators (if needed), clip board and pencils for judges
- Tape measure
- Team numbers for presentation space
- 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 – 2 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	
<b>1. Oral Presentation</b> 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	
<b>2. Display</b> 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	
<b>3. Display space is within listed dimensions</b> All points are awarded for this item if display is within the proper dimensions, and no points if it is not. (W-48, H-36")	10					
<b>TOTAL POINTS -- Possible/Awarded</b>	100	72	54	36	18	

## Appendix A

# Rare Disease Day 2019

## 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.

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### 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? What happened leading up to the diagnosis?  
(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 (eating, sleeping, moving about)?  
(Child's Name)
9. Does \_\_\_\_\_ go to school? 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. How has \_\_\_\_\_'s condition impacted your family?  
(Child's Name)
13. What does \_\_\_\_\_ like to do for fun?  
(Child's Name)
14. What are your concerns about \_\_\_\_\_'s future?  
(Child's Name)
15. What one thing could make \_\_\_\_\_'s life easier/better?  
(Child's Name)
16. What have you learned from being a parent of a child with this disease/condition?
17. Is there anything else you think we need to know or that you would like to share about \_\_\_\_\_ or your family?  
(Child's Name)

We really appreciate your time. We have been given the opportunity to present at Rare Disease Day on 2/28/19 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 2019

## 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.

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### 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

1. What is \_\_\_\_\_?  
(Name of Disease/Condition)
2. How many people have \_\_\_\_\_? How many patients with this condition are seen at Nemours?  
(Name of Disease/Condition)
3. How do patients get \_\_\_\_\_?  
(Name of Disease/Condition)
4. Will other family members get \_\_\_\_\_?  
(Name of Disease/Condition)
5. What current treatments are there for \_\_\_\_\_? What do those treatments involve?  
(Name of Disease/Condition)
6. Does the treatment for this disease/condition hurt the patient?
7. Do patients have to stay in the hospital for a long time?

8. Are there many researchers investigating this disease/condition?
9. Do you do research on this disease/condition? What kind of research?
10. Does someone fund your research? If so, who?
11. Are you working with any new drugs or doing clinical trials to see what might help this disease/condition?
12. Do you and other researchers work closely with families of patients and clinicians who provide treatment for these patients?
13. What is translational research and how might that help families of children with this condition?
14. What is the future direction of research for this disease/condition?
15. 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 2/28/19 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.