Nemours

Nemours Focuses on Rare Diseases: Students take the Spotlight

Rare Disease Day events let area teens shine

Wilmington, DE. (March 8, 2019) --Each year, Nemours/Alfred I. duPont Hospital for Children observes Rare Disease Day, February 28, by promoting awareness, advocacy and learning about rare diseases. Nemours has long been a resource for families of children seeking diagnoses, treatment, education and community for many rare conditions.

The hospital hosted the Beyond the Diagnosis traveling art exhibit featuring original portraits of children and teens with rare diseases. A portrait of patient Julie Gilligan, painted by Nemours research scientist Tariq Rahman, PhD, was added to the exhibit this year. Julie, 17, of Media, PA, has achalasia, a rare esophageal disorder, and is being treated by Nemours gastroenterologist Stephen Shaffer, MD. During an evening reception, Julie described her journey with achalasia and her portrait was unveiled. Then she and a contingent of students from her high school choir performed a few selections for an enthusiastic audience. Julie's is the second portrait that Dr. Rahman has contributed to the exhibit, which now includes more than 100 works of art.

For the fifth year running, Nemours also hosted a Rare Disease Day Student Research Event in coordination with Delaware HOSA - Future Health Professionals, in which 11 Delaware high school teams competed. The students were very well-prepared, having researched their topics, conducted interviews with clinicians, scientists and family members, and made visual and oral presentations. In addition, the students fund-raised to benefit rare disease research at Nemours. The team with the highest fund-raising total was Hodgson Vo-Tech High School, closely followed by Delcastle Technical High School.

The presentation winners were:

First: Newark Charter School – Sickle cell disease

Second: Conrad School of Sciences – Osteogenesis imperfecta

Third: Middletown High School – Retinitis pigmentosa

Following the awards, Delaware Director of Public Health Karyl Rattay, MD, and Bryan Gordon, representing Governor John Carney, proclaimed February 28, 2019 as Rare Disease Day in Delaware and presented the proclamation to Research Operational VP Vicky Funanage, PhD and Program Chair Terry Pedicone.

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