

## Art and Science

### Competing to raise awareness of rare diseases

“Art, whether it manifests as paintings, sculptures, poems, symphonies, or the care of patients, is a uniquely human quality.”

M Therese Southgate

Rare diseases are defined by the European Medicines Agency as around 7000–8000 mainly genetic conditions—often involving the nervous system—that need a complex clinical and therapeutic approach to management. In Europe, approximately 30 million people live with a rare disease. As symptoms for many rare diseases manifest at birth, these patients require: specialised care for their chronic and often disabling disease course; an articulated interdisciplinary integration to enable timely diagnosis; suitable programmes to reduce risk factors for congenital anomalies, extend screening available for newborns, and slow disease progression; and clinical and psychological management of the disease. Prompt diagnosis of rare diseases is crucial for reducing morbidity and mortality, to estimate the risk of recurrence, and to prevent further complications. Diagnostic delay or undiagnosed conditions, estimated to affect around 10%–30% of people with rare diseases, can have serious physical and psychological effects. People with rare diseases and their families often experience loneliness, tiredness, discouragement, mistrust of the health-care system, struggles at work, and societal inequities besides a number of medical issues. Health professionals, for their part, can also experience frustration, delusion, distress, and sense of defeat in caring for people with chronic, disabling, and often untreatable diseases.

The National Centre for Rare Diseases (NCRD), part of the Italian National Institute of Health (Rome, Italy), acts as the leading technical and scientific body of the Italian Ministry of Health and the National Health System. The NCRD supports public health through national and international activities, research, documentation, and training for health-care professionals focused on patient-centred care for people with rare diseases. Since 2008, the NCRD organises a national artistic competition, *The Flight of Pegasus*, dedicated to rare diseases. The aim of the initiative is to raise public awareness about rare diseases and empower communities through dissemination of scientific knowledge. This will support those communities to better handle complex medical information and cope with questions about rare diseases. The competition offers a variety of expressive formats, including narrative stories, poetry, drawing, painting, sculpture, photography, digital art, music composition, and music interpretation. Over the past ten competitions, the NCRD has collected a great number of contributions

judged by leading exponents of the artistic world. The intercultural networking at the event by attending artists, critics, musicians, curators, scientists, public and private institutions, patient organisations, and citizens represents an exciting opportunity where artists can promote their work and a wide range of people can get involved with creating and experiencing art and culture in the name of rare diseases. This year, a juried exhibition of a collection of past and current artworks took place at the Museo delle Civiltà, a public and research museum in Rome. A temporary one-month exhibition was held at the museum, attracting thousands of visitors; a printed catalogue collecting the exhibited artworks is under preparation to share with those unable to attend in person.

To foster a scientific milieu around the art competition, the exhibition concluded with a one-day conference, held on Rare Disease Day, on relevant issues relating to rare diseases. To capture both scientific and artistic interest, the one-day conference included four keynote lectures on humanities and rare diseases. In addition, relevant information on rare diseases was available for participants and visitors through interactive video stories and interviews. Just as high-quality scientific research blends creative and technical approaches to rigorous investigation, similarly, art combines inspiration with technical expertise. Fittingly for an event that unites science and art, there was a live musical performance—the Quartetto Guadagnini—which mixed technical expertise with artistic flourish at the opening ceremony of this year’s *Flight of Pegasus* exhibition.

Three insights emerge from this decade-long competition. First, every artwork tells a story and stories can



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The tenth edition of *The Flight of Pegasus* was partnered jointly with the Rare Disease International Film Festival. For more information see <https://filmfreeway.com/Unosguardoraro>

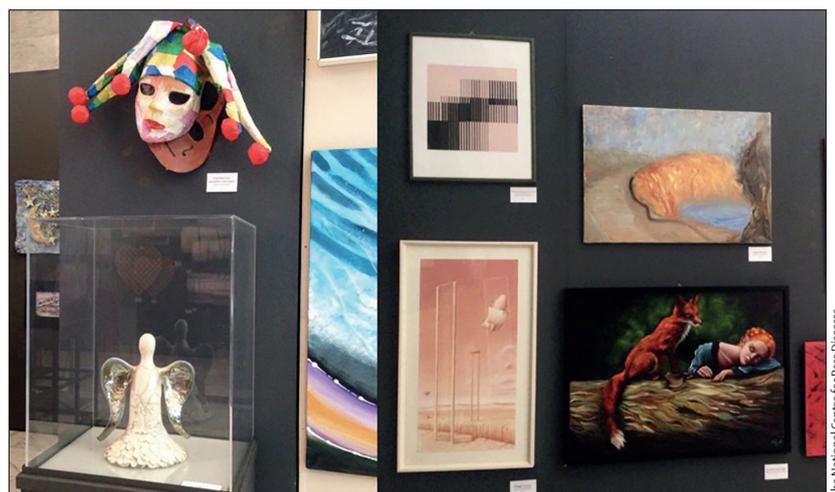
For more on **rare disease definitions** see <https://www.ema.europa.eu/en/human-regulatory/overview/orphan-designation>

For more on the **NCRD** see *Blood Transfus* 2014; **12** (suppl 3): s591–s605

For more on **The Flight of Pegasus** see <http://www.iss.it/pega>

For more on the **Museo delle Civiltà** see <http://www.museociviltà.beniculturali.it>

The more on the **Quartetto Guadagnini** see <https://www.quartettoquadagnini.com>



Collection of past and current artworks exhibited during the international competition *The Flight of Pegasus* held at the Museo delle Civiltà (Rome, Italy) in June 2018

For more on music-based interventions in neurological diseases see [Review](#) *Lancet Neurol* 2017; 16: 648–60

be a useful clinical tool. Narrative medicine can contribute to improved diagnostic accuracy, clinical decisions, and therapeutic alliance, and can reduce health-care costs. In recent years, there has been an increased interest in use of narrative medicine for people with rare diseases due to the development of precision medicine, rise of social media to promote narrative medicine in clinical practise, and a progressive shift towards a more participatory model of doctor–patient relationship where decisions are jointly made. In this respect, the stories told through the artworks from present and past *Flight of Pegasus* competitions emphasise the need for people with rare diseases and their families to receive better supportive care and to have a stronger social network. The collected artworks also highlight a number of positive achievements, including increased resilience, by people with rare diseases, their families and care givers, and health-care professionals. Thus, treasuring stories or artworks of people with rare diseases can help give clinicians to interpret and to understand the narrative of an illness, and can be a source of inspiration to humanise medical care.

Second, there is increasing evidence that artistic interventions might be beneficial to certain populations of patients. In the last decade, an increasing number of controlled studies have evaluated the potential rehabilitative effects of music based-interventions in various neurological disorders including dementia, Parkinson's disease, stroke, epilepsy, and multiple sclerosis. Individuals, especially children, with visual-spatial deficits—well known clinical manifestations of certain rare diseases—could encouragingly respond to special programmes of music performance. For example, multimodal educational methods including music

might be beneficial for patients with Williams syndrome, a rare genetic developmental disorder. Further investigation into the therapeutic role of music in some people with rare genetic diseases is being planned by the NCRD.

A better comprehension of the effects of musical activities and participation in other art forms might have implications not only for developing therapeutic interventions for rare diseases, but also for developing educational programmes. In this respect, the third insight gleaned from *The Flight of Pegasus* competitions regards its role as an interface between medicine and society to explore rare diseases. The award winners in the category of musical composition were two young musicians Yren Shen (Shanghai Conservatory of Music; China) and Linda Uran (Academy of Music, University of Zagreb; Croatia), who dedicated their works to encourage people with rare diseases to be resilient. A number of medical schools in the USA and in Europe encourage interdisciplinary and educational initiatives that integrate the humanities into medical education as an essential part of undergraduate study in their programmes. To this end, the NCRD welcomes high school students who are interested in science and medicine to join a special educational programme on rare diseases, narrative medicine, and medical humanities. As part of this programme, the NCRD provides narrative medicine training to students using a selection of artworks from *The Flight of Pegasus* competitions. This programme stimulates use of scientific methodology in approaching the subject of art, but above all instils in young students a cultural perspective of health and disease, explaining to what extent the humanities can inspire medical professionals to act with compassion and attention to detail as part of their interactions with people with rare diseases.

Rare diseases are unique, complex, and particularly demanding medical conditions whose main clinical manifestations or ensuing complications are not always obvious. The ability to understand clinical, laboratory, and imaging features of a rare condition, as well as to discern the most relevant information from a patient's history, all result from experience, but also represent key steps in the comprehensive training of young health professionals. In all these respects, a competition of arts dedicated to rare diseases helps to meet the desires, needs, and visions of patients, care givers, and health professionals.

The vigour and strength of the winged stallion Pegasus (the son of the sea god Poseidon in the old Greek mythology) make it a symbol of the transcendent side art and a source of inspiration for patients, families, and health-care professionals who face the everyday challenges of managing rare diseases, to rise indomitably, regardless of any obstacle related to their conditions, as the mythological Pegasus did.



The National Centre for Rare Diseases

The Quartetto Guadagnini at the opening ceremony of the competition at Museo delle Civiltà (Rome, Italy)—in the background a large polychrome window by Giulio Rossi (1897–1976)

Agata Polizzi, Amalia Egle Gentile, Domenica Taruscio