

# The FLIGHT of PEGASUS

13th edition

(2020-2021)

The artistic and music competition dedicated to rare diseases



The National Centre for Rare Diseases - Istituto Superiore di Sanità is pleased to announce the launch of the 13<sup>th</sup> edition of the artistic and music competition *The Flight of Pegasus* dedicated to rare diseases

## **ABOUT THE**

NATIONAL CENTRE FOR RARE DISEASES, ISTITUTO SUPERIORE DI SANITÀ, ITALY

The Istituto Superiore di Sanità (ISS) (National Institute of Health, Rome Italy) is the leading technical and scientific body of the Ministry of Health, the National Centre for Rare Diseases (NCRD) at the ISS sustains at national and international level public health actions, research programmes and outreach activities on rare diseases to ameliorate health and social care of people living with a rare disease.

## WHAT ARE RARE DISEASES?

Rare diseases are mainly genetic conditions with a complex clinical and therapeutic approach and relevant psychosocial consequences. In Europe, approximately 30 million people live with a rare condition, and yet a number of cases remain undiagnosed. With onset at birth or later, rare diseases require ongoing and specialised care for their chronic and often disabling course, as well as an articulated interdisciplinary health-care professionals integration. Current effort of the scientific community is mainly concentrated on studying the natural history of these disorders to identify the underlying causes, discover new efficacious therapies and improve the quality of life of the affected persons.

#### WHAT IS THE FLIGHT OF PEGASUS?

The Flight of Pegasus (II Volo di Pegaso) is the artistic and music competition, launched since 2008 by the NCRD to raise awareness of rare diseases.

This competition aims to provide expressive spaces to all people who, in various ways, face rare diseases or wish to learn more about these disorders.

The **key topic** of the 13<sup>th</sup> edition is the "**THE COLORS OF LIFE**" and all artworks must be inspired to this theme. Entries will be assessed for the art award by a judging panel of qualified experts.

The **award ceremony** will be part of a scientific and divulgative event that will take place in Rome, Italy (February 23, 2021), to celebrate the **Rare Disease Day 2021.** The programme will be published soon on the <u>competition website</u>.

All admitted artworks will be presented to the public at the award ceremony through a Virtual Exhibition and collected in a catalogue, published online on the competition website.

The winners of the competition will receive their certificate and plate at the award ceremony and will feature in an international peer-reviewed scientific journal.

The **intercultural networking** of the contest and of the final event, made by finalists, critics, musicians, curators, scientists, public and private institutions and citizens make *The Flight of Pegasus* an exciting occasion for artists to promote their art through many channels. At the same time, it represents a great opportunity to raise consciousness on rare diseases through different forms of art, consolidating the link between human relationships, social and healthcare.

#### WHO IS ELIGIBLE TO PARTICIPATE?

The competition is open to artists, amateurs, health-care professionals, patients, family members or anyone else wishes to participate.

There are no restrictions based on age, training or nationality. Only one artwork per artist may be entered into the competition. All works must be original.

## WHAT TO SUBMIT?

Drawings, paintings, sculptures, photos, digital arts, music compositions and interpretations are accepted.

A winning artwork will be selected for each section.

## **HOW** TO SUBMIT?

To enter please complete the registration form and submit files by www.wetransfer.com (see Terms and Rules) to: concorsopegaso@iss.it

by 11:59 pm (CET) on

(deadline extended)
DECEMBER 1, 2020

**ENTRY FEE:** none.

## **DATES AND DEADLINES**

- DECEMBER 1, 2020 Entry deadline
- February 1, 2021: Notification of admitted artworks
- February 23, 2021: Conference, awards ceremony and virtual exhibition of all admitted artworks

Please review our terms and rules for each section before starting your artwork.

For **more information** about terms and rules, technical guidelines, composition of jury, catalogue, delivery of artworks, copyright and restrictions, please, see the notice of competition at the web site.



<u>Website</u>



<u>IIVoloDiPegaso</u>



 $\underline{concorsopegaso}$ 



ilvolodipegaso



concorsopegaso@iss.it

TERMS AND RULES [1/6]

## INSTRUCTIONS FOR VISUAL ARTWORKS:

#### **DRAWING**

- Original and not circulated for professional or commercial purposes
- Indifferent technique (monochrome, polychrome, tempera, watercolor, collage, pastel)
- On support of paper or cardboard
- Any size

#### **PAINTING**

- Original and not circulated for professional or commercial purposes
- Indifferent technique (monochrome, polychrome, tempera, watercolour, oil, acrylic)
- On canvas
- Any size

#### SCULPTURE

- Original and not circulated for professional or commercial purposes
- Indifferent technique carving, molded, molds, casting, welding, assembly, installation) and material (wood, stone, wax, plaster, metal, plastics, neon, etc.),
- Any size

#### **PHOTOGRAPHY**

- Original and not circulated for professional or commercial purposes
- · In color or in black and white
- PRINTED on opaque photo paper
- Any size

#### **DIGITAL ART**

- Original and not circulated for professional or commercial purposes
- Any artistic intention,
- Realized through the use of digital technologies, manipulating videos, images, photographs, lithographs, drawings, with the aid of vector graphics software, using a mouse or a graphic tablet.



BEFORE completing the registration form, be sure you have:

[Section 1] The following **INFORMATION** to be transcribed into the registration form:

- 1. Description of the work (maximum 500 characters).
- 2. Indication of the rare disease or of the group of rare diseases to which the work is dedicated.
- 3. Biography of the author (maximum 500 characters).

[Section 2] The following FILES to be sent to <a href="mailto:concorsopegaso@iss.it">concorsopegaso@iss.it</a> by <a href="mailto:www.wetransfer.com">www.wetransfer.com</a>:

- 1. Form of acceptance and consent, filled online, printed, signed up, scanned (PDF format) and sent back.
- 2. A presentation with one or more high-quality digital photos (JPEG, PNG format; ONLY for Digital art: AVI, MP3, MP4, WMA format) of the artwork proposed, including title, year and characteristic (technique and dimension).
- 3. Front-back copy of an identity document of the author.
- 4. Recent photo of the author (JPEG, PNG format).
- 5. (ONLY PROFESSIONALS) Professional CURRICULUM and author's studies (PDF format, without length limits).
- 6. (ONLY MINORS) Form of authorization filled online, printed, signed up, scanned (PDF format) and sent back.

**Please note**: in the file of the artwork DO NOT indicate the author's name.



SEND ALL FILES indicated in section 2, to concorsopegaso@iss.it by www.wetransfer.com by 11:59 pm (CET) on

n (deadline extended)
DECEMBER 1, 2020

Please note: The registration to the competition implies the acceptance of rules described in the forms and in this call.

TERMS AND RULES [2/6]

## INSTRUCTIONS FOR MUSIC ARTWORKS

#### MUSIC COMPOSITION

- Original work, it may be already edited and/or executed but NOT AWARDED in other competitions
- · Any kind, aesthetics and style
- Organic PIANO and VIOLIN, GUITAR
- Duration between 6 and 8 minutes (exceptionally also of longer duration)

#### **MUSIC INTERPRETATION**

- Original EXECUTION/ARRANGEMENT/ELABORATION, it may be already edited and/or executed but NOT AWARDED in other competitions
- Any kind, aesthetics and style,
- Any organic with or without voice,
- Duration of between 6 and 8 minutes (exceptionally also of longer duration)



BEFORE completing the registration form, be sure you have:

[Section 1] The following **INFORMATION** to be transcribed into the registration form:

- 1. Description of the work (maximum 500 characters).
- 2. Indication of the rare disease or of the group of rare diseases to which the work is dedicated.
- 3. Biography of the author (maximum 500 characters).

[Section 2] The following **FILES** to be sent to <a href="mailto:concorsopegaso@iss.it">concorsopegaso@iss.it</a> by <a href="www.wetransfer.com">www.wetransfer.com</a>:

- 1. Form of acceptance and consent, filled online, printed, signed up, scanned (PDF format) and sent back.
- 2. A audio/video file of the artwork proposed, including title, year and characteristic (organic and duration).
- 3. Score of the artwork (PDF format).
- 4. Front-back copy of an identity document of the author.
- 5. Recent photo of the author (JPEG, PNG format).
- 6. (ONLY PROFESSIONALS) Professional CURRICULUM and author's studies (PDF format, without length limits).
- 7. (ONLY MINORS) Form of authorization filled online, printed, signed up, scanned (PDF format) and sent back.

Please note: in the file of the artwork and its description DO NOT indicate the author's name.

PILL IN the registration form on line at: <a href="https://it.surveymonkey.com/r/13thTheFlightOfPegasus\_RegistrationForm">https://it.surveymonkey.com/r/13thTheFlightOfPegasus\_RegistrationForm</a>

SEND ALL FILES indicated in section 2, to concorsopegaso@iss.it by www.wetransfer.com by 11:59 pm (CET) on

DECEMBER 1, 2020

Please note: The registration to the Competition implies the acceptance of all the articles described in the form and in the general part of this Call.

TERMS AND RULES [4/6]

# **ACCEPTANCE AND CONSENT FORM\***

The undersigne	d	born in	(State	),			
on/	/Resident - Country	City		(),			
Postal Code	Street		No, ID Card no				
participant to the	13 <sup>th</sup> edition of the Artistic and Music competition "The flig	ght of Pegasus", 13 <sup>th</sup> edition with the work entitled					
section		category	, having completed the online registration	form available at the link			
https://it.surveym	onkey.com/r/13thTheFlightOfPegasus_RegistrationForm	on/;					
		DECLARE					
	nd fully understood the Call of the Artistic and Music Conthrough the registration form and the acceptance and cor						
• to have read an	nd fully understood purposes and methods of the process	sing of personal data and to have had enough tim	e to decide, freely and voluntarily, whether or not to give	consent 🗆 YES 🗆 NO			
• to agree to participate to the 13 <sup>th</sup> ed. of the Artistic and Music competition "The Flight of Pegasus".							
services or oth	sent to transfer to the ISS the right to use the works (texer formats that become available in the future) for researce events and other initiatives.	ch purposes, training and scientific divulgation; ma	aking its work available at its own expense, according to	times and methods indicated by the ISS			
	ent to transfer to the ISS the right to use images of						
• to agree/conse	nt to the processing of my personal data for the purposes	s of the processing of personal data listed into priv	acy information at point n. 1	🗆 YES 🗆 NO			
• to agree/conse	nt to the processing of my personal data as specified in t	he Privacy Information at point n.3					
Date and place_				Signature			

# \* IMPORTANT

- IN CASE OF CO-AUTHORSHIP: print, compile, sign and send a FORM OF ACCEPTANCE AND CONSENT for EACH AUTHOR.
- > IN CASE OF artists under 18yrs: print, compile, sign and send a FORM OF AUTHORISATION signed by PARENTS.
- IN CASE OF SCHOOL CLASSES: print, compile and sign: a FORM OF ACCEPTANCE AND CONSENT filled out and signed by TEACHER together with an FORM OF AUTHORISATION FOR EACH AUTHOR under 18 yrs filled out and signed by PARENTS.

TERMS AND RULES [4/6]

# **ACCEPTANCE** AND **CONSENT FORM** (for artists under 18 yrs)\*

This FORM must be completed by parent(s) and/or person who holds the parental authority of the minor.

If the parental authority and / or death of one of the	e parents is decayed, it is COMPULSORY to	specify which of the follo	owing cases applies to authorize t	the minor:	
□ decay of parental authority (father)	□ death father	□ decay of pare	ntal authority (mother)	□ death mother	
The undersigned	born	in	(St	ate	),
on/Resident - Country		City			),
Postal CodeStreet			, No, ID Card no.		·
The undersigned	born	in	(St	ate	),
on/Resident - Country		City			(),
Postal CodeStreet			, No, ID Card no.		
As parent(s) and/or operator(s) the parental authori					
Music competition "The flight of Pegasus", 13th edition	with the work entitled				
section	category		, having completed the onli	ine registration form available at t	he link
to have read and fully understood the notice of the personal data collected through the registration form.					
<ul> <li>to have read and fully understood purposes and meth</li> </ul>	ods of the processing of personal data and to	have had enough time to de	ecide, freely and voluntarily, whethe	r or not to give our consent	🗆 YES 🗆 N
• to agree that our child/children (referred to as "Autho	r/s" / "Co-author/s") participates/participate to	the 13th ed. of the Artistic ar	nd Music competition "The Flight of I	Pegasus"	🗆 YES 🗆 N
to agree / consent to transfer to the ISS the right to u and support including CD-ROMs, electronic media, in expense, according to times and methods indicated by	nternet services or other formats that become	available in the future) for r	research purposes, training and sci	entific divulgation; making its wor	rk available at its ow
to agree/consent to transfer to the ISS the right to use of the authorization to use them.					
• to agree/consent to the processing of my personal da	ata and those of our child/children (previously	indicated as "Author" / "Co-a	author / s") for the purposes listed in	the privacy information at point n	1. 1 🗆 YES 🗆 No
to agree/consent to the processing of my personal data	ata and those of our child/children (previously	indicated as "Author" / "Co-a	author / s") as specified in the Priva	cy Information at point n.3	🗆 YES 🗆 No
Date and place		Signature		Signature	
* IMPORTANT					

- > IN CASE OF CO-AUTHORSHIP: print, compile, sign and send a FORM OF ACCEPTANCE AND CONSENT for EACH AUTHOR.
- > IN CASE OF artists under 18yrs: print, compile, sign and send a FORM OF AUTHORISATION signed by PARENTS.
- IN CASE OF **SCHOOL CLASSES**: print, compile and sign: a **FORM OF ACCEPTANCE AND CONSENT filled out** and signed by TEACHER together with aa **FORM OF AUTHORISATION** FOR EACH AUTHOR under 18 yrs filled out and signed by PARENTS.

TERMS AND RULES [5/6]

## **CATEGORIES**

• MINORS/AMATEURS. Less than 18 years on the deadline of the competition. [Exclusively for music sections] (S.8 and S.9), minor can apply to either beginner or professional category].

- ADULTS BEGINNERS/AMATEURS. ≥18 years completed on the expiry date of the competition announcement. They did not publish in publishing houses (S1, S2), they did not exhibit their works in art galleries, museums and sim. (S3, S4, S5, S6, S7), have not published in the recording area (S8, S9 (all sections). [Exclusively for music sections (S.8 and S.9), the "beginners" category is intended for both minors and adults].
- **ADULTS PROFESSIONALS**. ≥18 years completed on the expiry date of the competition announcement. They already have experience in the literary or artistic or musical field, demonstrable through publications, exhibitions, events and competitions in which they participated directly. [Exclusively for music sections (S.8 and S.9), the "professional" category is intended for both minors and adults].

## **SELECTION OF THE ADMITTED ARTWORKS AND WINNERS**

- The Organisers reserve the right to refuse any work that does not match the submission or the description on the basis of which it was selected.
- The winning artists will be selected at the discretion of the Jury on the basis of the entries submitted online by the candidates.
- The Jury consists of qualified members with different expertise such as curators or directors of art museums or foundations, journalists, art critics, gallery owners, exhibition curators, artists, intellectuals, writers, composers, musicians.
- Each jury member declares whether he or she has personal or professional relationship with the finalist artists. If this will be the case, the jury member will no submit his or her vote.
- The admitted artworks will be announced by February 1, 2021 on the competition website, social networks and individually by e-mail to the addresses indicated by the finalist artists in their respective submissions.
- The winners will be announced on the day of the awarded ceremony.

## ADMITTED ARTWORKS TO THE VIRTUAL EXHIBITION, POSSIBLE REQUEST FOR AWARENESS EVENTS AND INSURANCE

- The admitted artworks will take part to a virtual exhibition at the location and on the date indicated on the website home page of the competition.
- The admitted artworks may be eventually required by the Organisers for awareness events on rare diseases.
- In case the Organisers will eventually require the artwork to the artist for scientific purposes (i.e awareness events), the transport and handling of the works exhibited are organised and paid by the artists.
- The Organiser leaves the respective artists free to take out insurance against damage in transport, theft, fire and deterioration for the works exhibited or not.
- The artists release the Organiser from any responsibility for any damage that could have been covered by insurance taken out by the artist.

## **PARTICIPANT'S EXPENSES**

• The costs associated to travel and accommodation to participate to the scientific conference and awarded ceremony are not paid or re-funded by the Organisers.

TERMS AND RULES [6/6]

## PRIVACY INFORMATION

Related to the participation to the 13th edition of the Artistic and Music competition dedicated to rare diseases: "THE FLIGHT OF PEGASUS" (In accordance with the EU Regulation 2016/679 (GDPR) and the Italian Privacy Code, as amended by Legislative Decree 101/2018)

Istituto Superiore di Sanità (hereinafter "ISS"), registered office in viale Regina Elena n. 299 - 00161 Rome, C.F. 80211730587 - VAT number 03657731000 as Data Controller of the Artistic and music competition dedicated to rare diseases "THE FLIGHT OF PEGASUS", 13<sup>th</sup> edition organised by the National Centre for Rare Diseases, ISS, declares pursuant to art. 13 EU Regulation no. 679/2016 (hereinafter "GDPR") and to the Italian Privacy Code, as amended by the Legislative Decree 101/2018, that personal data will be collected and used for the following purposes:

## 1. Purposes and Legal Basis of the Treatment

Personal data will be collected by the ISS through the online registration form at https://it.surveymonkey.com/r/XIII\_VOLOdiPEGASO and will be processed exclusively for purposes related to the activities of the Laboratory of Health Humanities of the National Centre for Rare Diseases, ISS, including: research (e.g. thematic analysis of narrations); training (e.g. training courses for students, patients and healthcare professionals); scientific divulgation (e.g. publication of artworks, authors biographies and works descriptions in e-documents/scientific journals, social media, awareness-raising events).

ISS will also process the data referred to in point no. 2 only if necessary, for the realization of the competition and for scientific research/divulgation and training purposes.

The legal basis for the processing of personal data referred to in the point no. 2 of this privacy information is provided by the art. 6, par. 1, lett. a) GDPR, as "the data subject has given his explicit consent to the processing of such personal data for one or more specific purposes (...)".

The data subject has the right to withdraw his consent to participation, previously given, at any time and easily as they conferred and without undue delay, pursuant to art. 17, par.1, lett. b) GDPR.

However, this revocation does not affect the lawfulness of the processing carried out on the basis of the consent previously given and will have the sole effect of terminating the processing of the data subject's personal data for the future.

## 2. Categories of Personal Data

For the purposes referred to in point no. 1 and in the online registration form, the following categories of personal data and / or information may be collected and subsequently processed: personal identification information (name, email address, etc.) of author/co-author(s)/ teacher (in case of class participation), information related to one's biography (e.g. professional experiences).

#### 3. Method of treatment

The processing of personal data is carried out by means of the operations indicated in art. 4, par. 1, no. 2 GDPR such as: collection, registration, organization, storage, consultation, processing, modification, extraction, comparison, use, interconnection, blocking, communication, etc.

Data are processed by the ISS through IT, manual and paper methods, tools and procedures strictly needed to achieve the purposes described in point no. 1. The information collected may be disclosed and / or communicated through scientific publications, scientific conferences, etc., previously anonymised and only in aggregate form.

ISS provides physical, technical and organizational security measures pursuant to art. 32 GDPR, to prevent data loss, illicit or incorrect use and unauthorized access (Data Breach).

#### 4. Retention Period

Personal data will be collected for a period of time that suited to the purposes of the competition referred to in point n. 1 of this privacy information.

Only after appropriate anonymisation of the data, ISS can store the information obtained by questionnaire for studying and research purposes without limit, since the anonymous data, which can no longer be traced back to the data subject even indirectly, can no longer be considered as personal data and therefore subject to the discipline of the GDPR and the Privacy Code.

TERMS AND RULES [6/6]

#### 5. Access to personal data

The data may be accessible for the purposes referred to in point no. 1 only by authorized persons (e.g. responsible for the research project, researchers, collaborators) to the processing of personal data re the artistic and music competition "The Flight of Pegasus", 13<sup>th</sup> edition, organised by the National Centre Rare Diseases, ISS. The scientific responsible of the artistic and music competition "The Flight of Pegasus" is Dr. Domenica Taruscio - domenica.taruscio@iss.it.

#### 6. Rights of the data subject

The data subject may exercise data protection rights referred to in art. 15 GDPR et seq. More precisely right to access, right to rectification and updating, right to erasure, right to restrict processing, right to data portability, right to object to processing, right to lodge a complaint to the Guarantor Authority (art. 77 GDPR and 141 Privacy Code, as amended by Legislative Decree 101/2018).

## 7. How to exercise your rights

The data subject may at any time exercise its rights by contacting the ISS at: protocollo.centrale@pec.iss.it.

### 8. Identity and contact details of:

Data Controller - ISS

In the person of the President: Professor Silvio Brusaferro

E-mail: presidenza@iss.it

PEC: protocollo.centrale@pec.iss.it

Tel: 06 49901

## DPO (RPD) - SCUDO PRIVACY S.r.I.

In the person of the Legal Representative: Dott. Carlo Villanacci

E-mail: responsabile.protezionedati@iss.it

PEC: protocollo.centrale@pec.iss.it

## POSTPONEMENT, CANCELLATION, FORCE MAJEURE

- The Organisers reserve the right to postpone or cancel the scientific conference and the awarded ceremony if circumstances require it.
- The Organisers cannot be held responsible for any postponement or cancellation.
- In the event of an exceptional cancellation of the scientific conference and of the awarded ceremony, following a case of force majeure, the travel expenses of the participants will be not refunded by the Organisers.

## COMMUNICATION

- Press and public relations are handled by the Organisers of the competition and its partners.
- The artists taking part to the competition The Flight of Pegasus give the Organisers the right to reproduce the information presented in their submissions free of charge in perpetuity for promotional and awareness purposes in any medium, electronic or not (press releases, websites, social networks, catalogues, mobile applications etc.).

## **APPLICABLE LAW**

- These Rules are subject to Italian law. Any disputes that may arise between the Organisers and the artist(s) will be submitted to the competent national authorities.
- However, the Organiser reserves the right to take action before any other competent court.
- As these Rules are translated from Italian into English, the Italian-language version (available at www.iss.it/pega) is considered the reference version in the event of any dispute or translation error.

## **ACCEPTANCE**

• The artist declares that he or she has read these rules and expressly accepts them in full and without reservation.