

PRESS RELEASE

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AREA4HD International Festival: A Historic First Edition in Florence

The world's first festival dedicated to Huntington's Disease through art, research, education, and awareness

The AREA4HD International Festival — the first international event dedicated to raising awareness of Huntington's Disease (HD) through art, research, education, and advocacy, successfully concluded its inaugural edition in Florence, Italy, from 1 to 6 June 2026. Organised by the association [That Disorder – Global Human Community](#), the festival was held under the patronage of the Municipality of Florence and brought together participants from across the world, including Australia, the United Kingdom, the United States, Venezuela, Poland, and Denmark.

The event was attended by representatives of patient and advocacy associations from across Italy and beyond, further strengthening the sense of the international community around HD

The festival was preceded on 31 May by the illumination of the historic Tower of San Niccolò in blue and purple, as part of the global #LightItUp4HD campaign promoted by the Huntington Society of Canada, bringing the HD community's colours to one of Florence's most iconic landmarks.

A Week of Art, Science, and Advocacy

Over six days, AREA4HD brought together an exceptionally wide range of artistic disciplines and formats, all united by a single purpose: making Huntington's Disease visible. The programme included:

- Four photography exhibitions brought the visual heart of the festival to some of Florence's most iconic venues: *Borderless* by Gabriele Berti, documenting the everyday life of families affected by HD across six countries; *Beyond the Inheritance* by Vladimir Marcano and *Barranquitas: Magic Realism* by Gindel Delgado, both bearing witness to the Venezuelan HD community at Lake Maracaibo; and *Hidden World of Huntington's Disease* by Edith Cowan University (Australia), using the photovoice method to give voice to patients, caregivers, and researchers.
- A photography contest *Beyond the Frame, Within the Journey*, showcasing works by patients, families, and caregivers affected by movement disorders, selected by an internationally renowned jury: Edoardo Agresti, Lynn Johnson, and Vladimir Marcano.
- Documentary screenings: *The Light*, a documentary by Gindel Delgado, tells the story of the Caregiver Program funded by Factor-H and directed by Alex Fisher,

following two informal caregivers in Barranquitas, Venezuela, the community with the highest known incidence of HD in the world; *L'Attesa (Anticipation)*, produced by That Disorder – Global Human Community, is a cross-cultural documentary filmed between Florence and Istanbul. A diagnosis of Huntington's Disease suspends time, and existence becomes trapped in anticipation. Through the stories of Turkish and Italian families living with HD, the film documents how mutual listening can transform a solitary sentence into a shared landscape.

- A full-day cinema and human rights workshop led by Emmy-nominated filmmaker Gindel Delgado
- Seminars on graphic novel, photography, neuroaesthetics, and creative languages in rare disease communication
- Presentation of the Caregiver Program by Alex Fisher (Factor-H), recipient of the Amgen Prize for innovation in rare disease patient support
- Live music by Prof. Flaviano Giorgini (University of Leicester), neurogenetics researcher and musician
- The dance performance *Hold me Tight*, by Venezuelan artists Viola Panik and Mr. Punch, explored the evolution of intimacy within a couple as HD progresses, the touch that begins as love and attraction gradually transforming into protection, care, and the management of daily life.
- *Carolyn*, a contemporary art installation by Nadia Markiewicz, part of That Disorder's LOVE&JHD programme, presented a projection of photographs documenting the collection of death-related objects assembled by Carolyn Josephine Goracy in the final years of her life, as she battled juvenile Huntington's Disease until her passing at age 31.

Scientific Conference: The Visible Gene

The closing day (6 June) hosted the scientific conference *Il Gene Visibile: art and research in Huntington's Disease*. Two sessions brought together researchers, clinicians, patient advocates, and association representatives from across Europe and beyond, covering somatic instability, cognitive change, physical activity in HD, intimacy, rare disease frameworks, and art-based approaches in long-term care.

Key Partners and Collaborators

AREA4HD was built as a shared platform for the entire HD community. The festival received the official patronage of the Municipality of Florence, the Tuscany Region, AOU Careggi, EHDN, HDYO, and EHA. Partners and collaborators included Factor-H, Edith Cowan University (Australia), OMAR – Osservatorio Malattie Rare, the Fresco Parkinson Institute, kbo-Isar-Amper-Klinikum di Taufkirchen, the Polish Huntington's Disease Association, and Camera38, a non-profit organisation dedicated to photography. The festival received regional television coverage.

Voices from the Festival

“AREA4HD was born from a personal place — from living with the knowledge that Huntington's Disease is part of my future. But from the very beginning, we wanted to transform something deeply personal into something collective. Seeing artists, scientists, families, and advocates from across the world converge in Florence around a disease that has for too long remained invisible is something we are immensely proud of. This is just the beginning.”

— Gabriele Berti, President and Founder, That Disorder – Global Human Community

About That Disorder – Global Human Community

That Disorder – Global Human Community is a Florence-based non-profit organisation, operating globally, dedicated to raising awareness of Huntington's Disease through art, advocacy, and community-building. Through its different programmes, the association works to reduce stigma, strengthen the HD community, and build bridges between science, art, and society.

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Photos available on request. High-resolution images can be provided for press use.