





## Introducing "NOI HUNTINGTON – La Rete Italiana dei Giovani – The Italian HD Youth Association"

Alessia Migliore<sup>2</sup>, Barbara D'Alessio<sup>1</sup>, Marco Salvadori<sup>2</sup>, Marina De Marco<sup>2</sup>, Osvaldo Tassano<sup>2</sup> 1) LIRH Foundation, Rome and 2) NOI Huntington association, Rome.



«We are boys and girls sharing the experience of HD. We live in different cities and are 15 to 35 years old. We know there are many others 'like US': we would like to know them, because we believe we are stronger together. Together, we can do what it is better for US. Together, we can help others living our own condition. Together, we can face all the obstacles we will find in front of US.» Our motto is:

«Nessun Huntington è solo se ci siamo NOI» (No HD affected person is alone anymore thanks to us)

Objectives: 1.Set-up a national youth network to offer to children and young adults (no matter if they are affected or at-risk) the opportunity to know each other, to meet and talk with no shame and no fear, and to develop HD educational programs; 2.Raise awareness about HD, through social networks, public events, etc.; 3. Share the results of the scientific researches in plain language; **4.**Collaborate with other associations worldwide.



From the left: Marco, Alessia, Catherine Martin (HDYO), Marina.

**Methods:** We use the social networks to communicate our initiatives and to offer support to whoever needs or asks for it. It is not needed to be a member to get in contact with the association!

We organize events to raise awareness about HD and we participate to events related to HD.



In front of St. Peter's Basilica after the General Audience.

2019 Achievements: In May 2019 the association organized the first "HD on the bike" in Italy (Florence), in collaboration with LIRH and under the umbrella of the European Huntington Association. It was an emotional two-day event covered by both national and local media: a bicycle tour from Florence to Campi Bisenzio (where one of LIRH Foundation HD outpatients service is located), with all the participants dressing a t-shirt especially made for the event; an open day in the magnificent St. Minias on the Mountain's basilica.

In September 2019, we were invited to attend a Holy Father Pope Francis General Audience in Rome.



HD on the bike, Florence 2019.

**Future Plans:** Started in 2018, the association is growing up, with new members joining in 2019.

We are planning other initiatives in the coming future, like attending to the first HDYO conference in May 2020.

Stay tuned and follow us on our social network pages for update!







