

SPAZIO HUNTINGTON – A Place for Children

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Rationale

Now we know that paediatric HD is different both from adult and also from juvenile onset HD – further information are absolutely needed in order to properly face this disease in terms of clinic and future possible therapeutic perspectives



Objectives

- To contribute to a better knowledge and understanding of paediatric HD -
- To get in contact with those families whose children are, or could be, affected by HD -
- To give them the best possible care and hope for the future -
- To collect data for research purposes -



“To catch the many and still unknown clinical implications of paediatric HD it is necessary to come in contact with children, but we must avoid the risk of causing them a negative psychological fallout”, stated Dr. Squitieri



“It was almost like being at home. For the first time, my daughter met another girl with the same illness and played with her. I invite all the mothers who live the same condition not to be afraid and to contact the toll-free number 800.388.330 to learn more”, said Silvia, mother of a 8 year old daughter, after experiencing ‘Spazio Huntington’



From Left: Dr Simone Migliore (CSS), Dr.ssa Federica Gaziola and Dr. Alessandro Capuano (Bambino Gesù), Maria Gabriele (LIRH), mothers, grandmothers and children. Dr. Ferdinando Squitieri (CSS/LIRH)

Methods

We have launched a **partnership with Bambino Gesù**, one of the most important and internationally recognized Paediatric Research Hospital –

The **HD experts** (Dr. Ferdinando Squitieri and his team) work in a close collaboration with their neurologists and child psychiatrists, who have **expertise on paediatric rare diseases** – We identified **LIRH Foundation site** – which is not a hospitalized environment - as the right place where: **HD families** with children can meet, with us and with each other; **children** can play and have fun; **researchers and professionals** can visit, monitor and collect information on children; **LIRH staff** can look after families and children.

Achievements

Even tough Spazio Huntington was launched only few months ago, we already got in contact with about 30 minors and their affected/at-risk parents. We believe this initiative may represent a way to break the wall of parents' fear and to effectively face the most aggressive and overlooked HD variant.

Fondazione Lega Italiana Ricerca Huntington (LIRH Foundation) offers care, promotes research and education on HD at a national and international level, being driven by families, researchers and health care professionals together. It is also a network of patients associations, which include LIRH Toscana, LIRH Puglia and NOI Huntington, the Italian Youth HD Association.