

Duccio Cavalieri

AMORHI-ONLUS Associazione Italiana Morbo di Hirschprung.

<https://amorhi.org/>

Amorhi stems from the Associazione Amici di Francesco Onlus, the first Hirschprung patients association in Italy



ABOUT MY ROLE as ePAG in ERNICA:

1. Patient Representative for the Italian Patients association Amorhi
2. Member of the workstream on Intestinal diseases (area of focus enterocolitis in HSC)

MY STORY:

I was born in 1966, I am a scientist, microbiologist and a yeast geneticist. Following a Phd in Genetics at the University of Pavia, I was group leader and Harvard Fellow at the Bauer Center for Genomics, Harvard University, Boston. In 2005 I went back to Florence University as professor of microbiology (www.duccioknights.org). In 2005 my son Giovanni was born with long Hirschprung. Following three surgeries in Florence, with resection of several parts of the Ileum and Colon, in 2016 we moved to Gaslini Hospital in Genova where he was finally diagnosed with long Hirschprung and total colon aganglionosis. Following total colon resection, as a consequence of the several surgeries Giovanni had enterocolitis and secretory diharrea and was in a regimen of parenteral nutrition for two years. Since then, thanks to the pioneering work of Prof. Vincenzo Jasonni and Alessio Pini Prato from Genova, and Paolo Lionetti from Florence, I experienced first hand the potential of an interdisciplinary approach to help patients, in particular the difficult ones. This led me to change focus of my scientific career and start to study the role of the microbiome in colorectal disorders, including Hirschprung. I am now working on microbiome intervention strategies for treatment of enterocolitis in HSC patients.

I was member of the first Italian association of Hirschprung patients, Amici di Francesco. I am one of the founding members and of the board of directors of the new Hirschprung scientific patient's association, Amorhi, where I also lead the scientific advisory board.

I am a passionate advocate of interdisciplinary and international collaboration; I consider of paramount importance the sharing of good practice and the involvement of patients and families in the development of best practice, interdisciplinary approaches to handle complex and rare disorders. ERNs are, in my view, a most welcome initiative and ERNICA provides an unprecedented opportunity for those born with Hirschprung and the other conditions within its remit.

I have worked for all my life in the context of large European Networks of excellence, and I am deeply convinced that interdisciplinary research is the only path to the future for those suffering from rare diseases.

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