

Nicole Schwarzer

SOMA e.V.

**SELBSTHILFE FÜR MENSCHEN MIT ANOREKTAL-
FEHLBILDUNGEN UND MORBUS HIRSCHSPRUNG**

(Patientorganisation for people with anorectal

maloformation/Hirschsprung Disease) www.soma-ev.de



SOMA e.V.



ABOUT MY ROLE as ePAG in ERNICA:

1. Member of the Advisory Board as Patient Representative for all diagnoses in ERNICA
2. Member in Workstream: malformations of the digestive system – Working Group Intestinal diseases
3. Member of the Working Package Standards of Care for the Working Group intestinal disorders/Hirschsprung disease

and member of the eUROGEN – Network – Workstream 1: Rare Congenital Uro-Recto-genital (for anorectal malformations)

MY STORY:

Nicole Schwarzer studied history (1984-85) at the Ludwig Maximilians University in Munich, Germany, and Fundraising Management (2001-03) at the Fundraising Academy in Frankfurt, Germany. She worked in different fields; from 1989-93 for a publishing company, and from 2003-10 for the Academy for Psychotherapy of Children and Adolescents in Munich, Germany.

After her youngest child was born with an anorectal malformation in 1997, she started to work for SoMA – the German self-help organization for people with anorectal malformations.

Since 2000 Nicole Schwarzer is chairwoman of SoMA. In this function she not only heads this organization with now over 1000 members, but is also involved in CURE-Net, a research project for uro-rectal malformation (sponsored by the German government) and in ARM-Net, a European Network project for anorectal malformations. She gives presentations at the Colorectal Club as well as other national and international congresses on a regular basis; and together with her SoMA team she develops and implements various support projects, giving people with anorectal malformation (ARM) and Hirschsprung´s Disease (HD) a positive perspective and a higher quality of life.

Since the beginning of the developments of the European Reference Networks she is, together with the 2nd chairwoman of SoMA, Annette Lemli, active in the both networks eUROGEN and ERNICA

“Today I’m very happy to see in CURE-Net, ARM-Net and the ERNs so many dedicated people from so many different countries – all of whom are committed to the research of anorectal malformations and working for a better life for people with ARM/HD. People with this rare handicap – which is still treated as a taboo – have the same right of being in the focus of medical researchers and professionals as other patients do. I’m positive that in 20 years from now parents will know more about this disease – and will get optimum treatment if their child is born with such a malformation.”

How to contact me:

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