


Annette Lemli

ERNICA patient representative (/ePAG representative) for intestinal diseases,
co-lead of the intestinal diseases workstream and deputy ePAG lead



In 1993 my son was born with an anorectal malformation (ARM) and other congenital malformations. Until then I had been working as a purchase manager. Due to numerous hospital stays and operations I had to stop my work at that time. Since 2006 I have been a Board Member of SoMA (the German patient organisation for anorectal malformations, Hirschsprung's Disease and cloacal exstrophy). Since 2010 I am the 2nd Chairwoman of SoMA, among others responsible for financial matters, follow up projects and patient counselling. Together with our team we develop and implement various support projects and try to give people with ARM, HD and cloacal exstrophy a positive perspective and a higher quality of life. Our goal is that every patient does not feel alone and is operated and gets follow up in a centre with high expertise in the treatment of these rare diseases. Since the beginning of the development of the European Reference Networks we are, together with the chairwoman of SoMA, Nicole Schwarzer, active in the two networks eUROGEN and ERNICA. In our opinion this is a huge opportunity for an international collaboration between healthcare professionals, patients and policy makers for the benefit for the people born with rare and complex diseases.

Disease representing:	Hirschsprung's Disease (HD)
Patient organisation:	SoMA e.V. Patient Organisation for People with Anorectal Malformations, Hirschsprung's Disease and Cloacal Exstrophy www.soma-ev.de 
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