

NECESSITY PROJECT : PATIENT ADVISORY GROUP (PAG) MEMBER ROLE

PAG description	Group of patient representatives from several ISN (International Sjögren's Network) organizations.
Role	<ul style="list-style-type: none"> To support the goals of the Necessity project elaborating new primary end-points in Sjogren's syndrome To support the dissemination and use of the results of the project among patients, health professionals, healthcare purchasers, providers and the public.
Organizational position	The AFGS is a participant of the project on behalf of the ISN. The PAG will collaborate with the AFGS in this context.
Responsibilities	<p>To facilitate/contribute to the following:</p> <ul style="list-style-type: none"> Review the project documents relating to patients' involvement. Collect information, organize surveys within his/her organization. Exchange information within the ISN. Liaise with Health Professionals, Health Authorities and Payers in his/her country. Participate to the organization of workshops with Health Professionals, Health Authorities and Payers. Attend the relevant workshops when needed. Raise awareness about Sjögren's Syndrome and disseminate Necessity's achievements.
Tools	<ul style="list-style-type: none"> Through e-mail, SMS, Skype, WhatsApp, telephone. Personal computer with efficient protection software. Participation to meetings/workshops. Volunteer work. Travel expenses will be covered subject to prior written agreement.
Knowledge	<ul style="list-style-type: none"> Written and spoken English. Proficiency in MS Office (Word and Power Point in particular). Use of social media. Appreciated: scientific culture and project management understanding.
Skills and Abilities	<ul style="list-style-type: none"> Experience with Sjögren's Syndrome Patients' perspective. Ability to motivate, lead a group and create lasting relationships with the other patients. Ability to analyze information and transmit what is important. Organizational skills. Advocacy abilities.
Personal attributes	<ul style="list-style-type: none"> Able to work internationally and adapt to different cultures. Motivated and persevering. Able to travel in Europe and the USA. Able to arrange personal health, travel and liability insurance.

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