NECESSITY PROJECT: PATIENT ADVISORY GROUP (PAG) MEMBER ROLE

<table>
<thead>
<tr>
<th>PAG description</th>
<th>Group of patient representatives from several ISN (International Sjögren’s Network) organizations.</th>
</tr>
</thead>
</table>
| **Role**        | • To support the goals of the Neccesity project elaborating new primary end-points in Sjögren’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** | To facilitate/contribute to the following:  
                                  • 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**       | • 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**   | • 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** | • 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** | • 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. |

Version V1.0  20 February 2019