PATIENT CENTRICITY IN ACTION

Patient voice program in FOP

Experience map of Fibrodysplasia Ossificans Progressiva (FOP) for people living with the condition and caregivers.

RARE DISEASE

Rationale

Ipsen started this project to understand the experiences of people living with FOP in Spain at the time of diagnosis. The aim was to help raise awareness of the condition and support early diagnosis and appropriate referral, as well as identify where people living with FOP need more support.

Co-creation

The project was created through a collaboration with the Spanish Patient Association, Asociación Española de Fibrodisplasia Osificante Progresiva (AEFOP), who helped to identify four people living with FOP and six caregivers. AEFOP will also collaborate with Ipsen on the analysis phase of the project, helping to co-create solutions to support people living with FOP.

Project description

Phase I: individual interviews were conducted to understand management of FOP, from diagnosis to living with the condition, capturing individual experiences and identifying regional differences.

Phase II: a focus session group was held to validate and build the experience map and collect actionable insights from the perspective of people living with FOP, helping Ipsen to design valuable patient programs.

Impact/results

- **74 insights** were collected during different phases of the disease: pre-diagnosis, diagnosis, post-diagnosis and living with FOP.
- **12 actionable ideas/initiatives** to cover: disease awareness, early diagnosis and identifying people living with the condition, healthcare professional (HCP) and patient education, networking and referral.

Learnings and next steps

Next steps for this project include:
1. Further analysis of collected insights.
2. Parallel investigation with HCPs.
3. Collaboration with AEFOP to co-create valuable solutions for patients.

> We are very committed to focusing attention on knowledge of FOP and thereby supporting patients and their families to improve FOP patients' lives.

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