ASSOCIATION ALBI

- Representing **4 rare inflammatory liver diseases :**
  Primary biliary cholangitis, Primary sclerosing cholangitis, Autoimmune hepatitis, Low Phospholipid-Associated Cholelithiasis
- A community of **3000 people** (website, forum, Facebook, Twitter, newsletters…)
- **850 members**
- **20 volunteers** - regional ambassadors
- **Association certified** by the French Health Ministry to represent patients in health organisations
- Member of French Liver Network **Filfoie** and French network for inflammatory diseases of liver and biliary tracts - MIVB-H – equivalent to a pilar within the 'filière' and **ERN RARE-Liver**

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CONDUCTING SURVEYS SINCE 2005

2005	• Quality of Life • Hierarchy of the symptoms and patients' difficulties	100

2010	• Quality of Life (with BVA – survey company)
	  • 241 ALBI patients and 243 respondents from control group
	  • Recognition of the problem of chronic fatigue
		484

2014	• Psychological impact • 50% anxiety, 25% depression	264
2017	• Patients' major concerns • Disease progression, treatments, not symptoms	350
2018	• Quality of Life • Panorama of the 4 diseases	600
2018	• Priorities for the PSC research • Common survey with UK and US patients groups	370
2020	• Study about patients' experiences on PBC treatments	700
2021	• Medical care in France – medical visits • Basis to re-certification of centres of expertise + progress plan	700
2021	• Study about reimbursement expenses ALD • Quantity and reasons for a problem in the 100% reimbursements	700

MEDICAL CARE: EVALUATION OF CENTERS OF EXPERTISE

Assessing patients’ care in 35 centres of expertise (medical visits) and others

> Used in the re-certification of those centres as part of the French ‘filières’ (ref. networks).

experience from the **EURORDIS AMEQUIS group** for the assessment, monitoring & evaluation of ERNs.

Questionnaires (26 closed-ended questions + sev. open-ended questions), sent by email, Facebook and added on the website (2 months fieldwork): **700 respondents**

Use of the results

- Presentation to the French liver network and AILD network coordinators.
- Publication on website, Facebook, forum + sent by email to contacts.
- Exchanges with network coordinators and centre leads (ongoing)
- Used in personalised letters of support for the re-certification of French centres
- Used in progress plan to be implemented in 2023.

CONCLUSIONS

Develop a culture for people in the community to express themselves, be listened to and show them that their voice is taken into account:

- Regularly **ask** the community what they think and what they experience
- Make the community feel **listened to** e.g. by answering their comments in the open questions when they give their email, sending them results and telling them how those results are being used…
- **Use the survey results for action**: QoL (chronic fatigue), making sure that patients' feedback is taken into account during visits…
- **Take the experience into account** when doing new surveys (zooms) and when dialoguing with clinicians and researchers, as well as supporting patients.

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