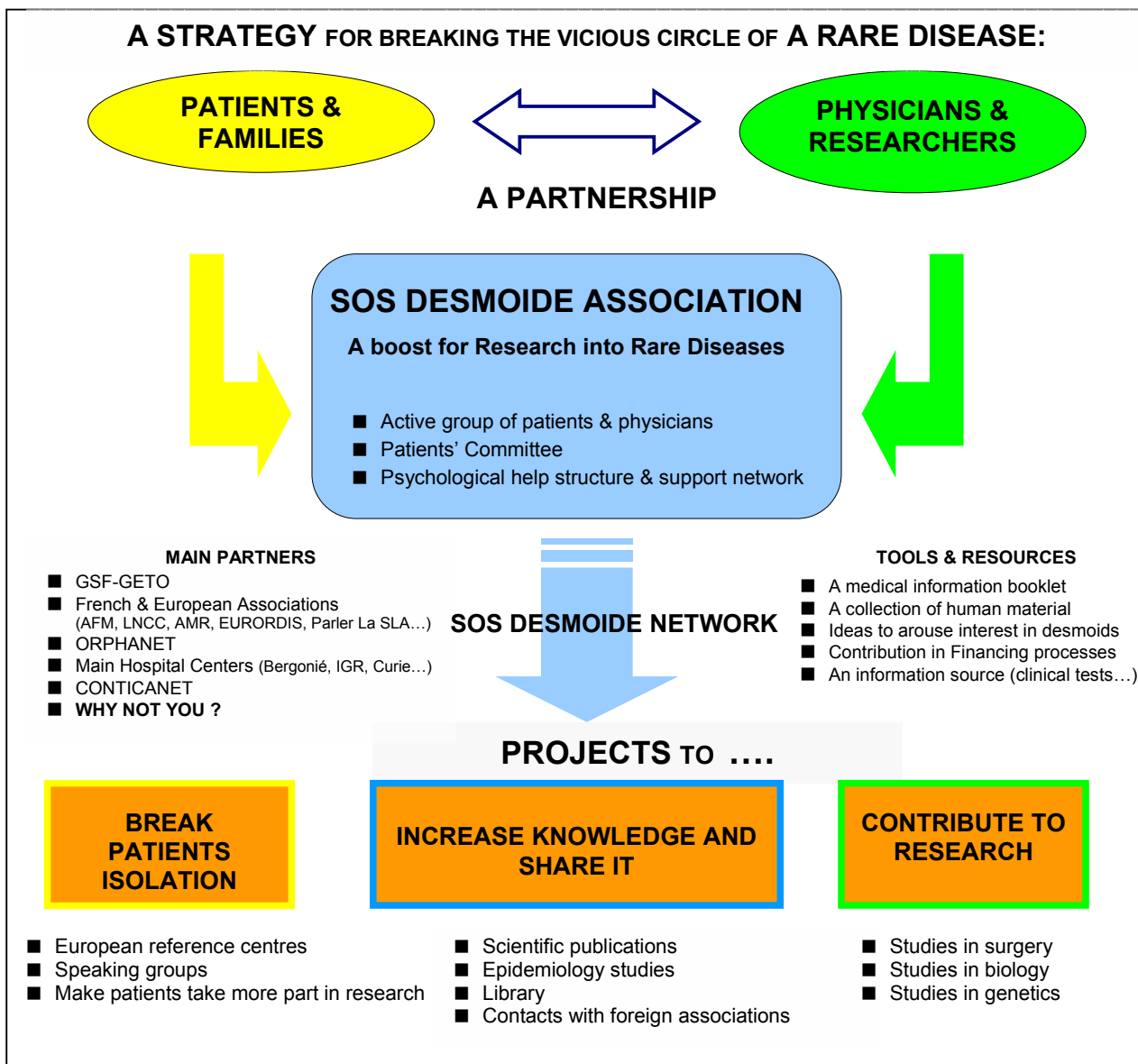


"SOS DESMOIDE": A FRENCH PATIENTS' GROUP FOR DESMOID TUMOUR PROMOTING RESEARCH, SUPPORTING PATIENTS

Contributors : SOS DESMOIDE ASSOCIATION

ORGANISATION	ACTIVITY
President & Founder : Marie PODEVIN-LEMARCHAND (patient) General Secretary : Dr Laurent MIGNOT (physician) Patients' Committee Psychological Support Structure	Creation date : November 1998 Members : 250 Patients who have contacted our association : 270 Core members : around 15 (including 6 physicians)

FUNDAMENTAL GOALS		
Break patients isolation Inform on illness & orienting Bring psychological support Make patients contribute to research	Collect & share knowledge Gather patients' stories & doctors' experiences and results Improve understanding of desmoids Circulate new data	Stimulate & promote research Arouse interest in desmoids Run an active support group Help the development of research programs



WE NEED...

- More physicians & researchers from France & Europe to work on desmoids
- Official organised network & partnership on desmoids
- New communication tools for physicians
- Help to expand the tissue bank & start DNA collection
- More human and financial resources

JOIN US....

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