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French experience with rare diseases plans

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The first French national plan for rare diseases (2005-2008) laid the foundations for Rare Disease (RD) specific activities, mainly by creating centres of expertise. The second plan (2010-2014) aims at building the RD world of tomorrow on the foundations of the first plan taking into account its achievements and pitfalls.

RD patients are rare, as are RD experts. Building, maintaining and spreading expertise requires a constant equilibrium between up-hill and down-hill.

Up-hill is filling the gap between patient care and the tremendous fundamental progresses which can come from a close connection with fundamental research, and academic and/or industrial groups involved in orphan drugs or new therapeutic approaches. The main achievements of the first national plan have been a large support for research including therapeutic trials, for genetics labs and building animal models.

The main projects for the second plan are to create a foundation for scientific cooperation which deals with advising for scientific projects and grant submissions, of helping with access to highly specialised tools and promoting partnership between academic and industrial stakeholders.

Down-hill is the use of expertise for improvement in patient's quality of life, from centres of expertise to the patient's home. Spreading information and guidelines is time consuming, and involves several levels of actions. The first plan's main achievement was the identification and support of 131 centres of expertise and their network of 500 «Competences» centres; the increased financial support to Orphanet; and the improved connection between patient organisations and experts.

The Second Plan's main projects are to establish national networks for dissemination of expertise, information, and therapeutic education as well as neighbouring assistance for home care and day to day problems.

Moreover it has to be emphasized that expertise is bicephalous, involving both specific clinical management and biological assessments by highly specialised and constantly evolving techniques. The second plan will officially recognise such synergies.

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