

afph
ALLIANCE FOR PULMONARY
HYPERTENSION

The French pH patient association
experiment of pioneering

HTaP France

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Context at the end of the XXth century, landscape from where it all started....


- PAH described for the 1st time 1891
- WPHS Geneva 1973 : *Primary pulmonary hypertension is a rare disease total number of case report to date is of the order of hundreds.*

- In practise : not known as a disease : just symptom with bad prognosis
- Echocardiography was not routine before the 80's
- Only electrocardiogram, x-ray and catheterism
- Only calcium blockers


PRIMARY
PULMONARY
HYPERTENSION

Report on a WHO meeting
Geneva, 15-17 October 1973

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WORLD HEALTH ORGANIZATION
GENEVA
1973



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As Knowledge on PAH improves...

First heart-lung transplant (1981-1986)




First medicine epoprostenol (Flolan) approval 1995 (US) 1998 (France)

WSPH 1998 Evian – new classification – no more « primary » or « secondary » PAH but PAH or associated pulmonary hypertension : a clinical classification

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First steps of the French patients Association

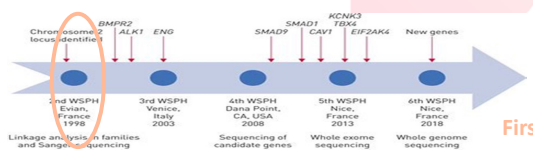




1996 **PHA** invited the French representatives:
Pr Duroux sent Dr François Brenot and Nicole Cabon (†) and her husband


Creation of Association des patients souffrant d'hypertension artérielle pulmonaire , domiciliated in Clamart (Hospital Antoine Bécclère)

Very small budget ± 1000€
Depending on personal means, hospital, ...
1 GAM every year + medical presentations
Cap Vers... magazine 1st issue 2nd semester 1997



First medical announcement 1998 ?



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Structuration of the French patients Association

2001 www.htapfrance.com needed €€€ !

First official sponsor Glaxo Wellcome (GSK)

2002 Evolution of the association

- New name, new logo, new statutes, new address outside of the hospital
- New organisation
- A few hours salaried work
- Budget still small ±15000€
- Learning independence from physicians and from sponsors

First regional meeting: already international ⇒

Second official sponsor Actelion Pharmaceuticals, France

2003, Brussels November 28th : creation of PHAEurope, umbrella organisation a group of PH patient associations

Organised by Bruno Kopp from the German association and welcomed in Vienna by Gerry Fischer on the occasion of ERS, co-facilitated by Pr Gerald Simonneau.

Creation of a newsletter *Brev'info*

2004 creation in France of the rare diseases network

1 reference center, 22 competence regional centers

2005 First meeting of our Scientific Committee 13 members



n.B : 1996-2012 French association participated to PHA conference

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New steps for HTaPFrance

2006 10th anniversary Miss France

2007 Salaried director

New logo, new president etc..

A couple more sponsors and partners (Kiwanis, Rotary, Lion's, various associations...)

Labelisation of the association as official representative for patients in hospitals

Budget ± 100 000€

More support & communication with research team (INSERM unit)

2010 first patients national conference (Paris 2010)






Social media

PH events « A pleins poumons »

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HTaPFrance continued : challenges

**More transparency, diversification of funding
volunteering & profesionalisation**

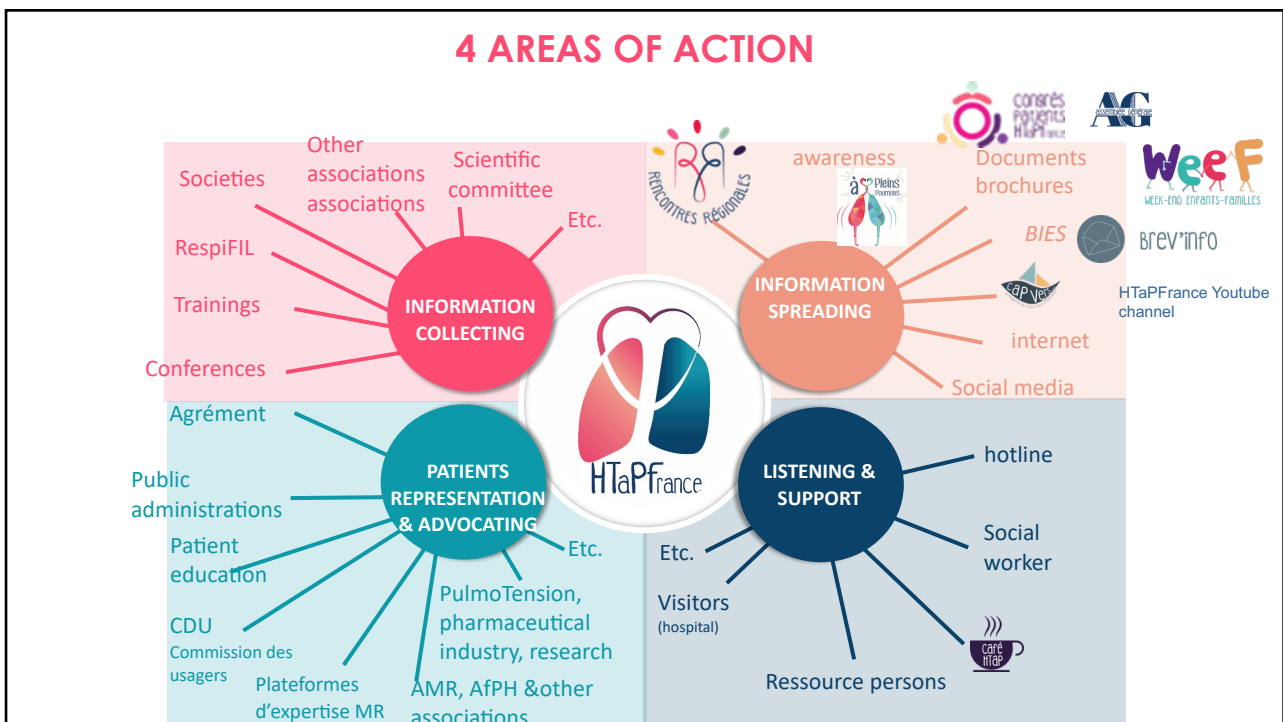
**Sense for the patients & carers
Collaboration
Quality of life**

And still, after all, a teamwork

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Thanks for your attention !

Awating your questions

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