



# PRIOR-RH

## A Regional Centre for People Living with Rare Diseases

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**EURORDIS**  
Rare Diseases Europe

EURORDIS Membership  
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# PRIOR – RH

- Regional Centre
- Information
- Guidance
- for Rare Diseases
- and Rare Handicaps
- Pilot Experiment



# PRIOR (2009)

- 1<sup>st</sup> National Plan for RD 2005 – 2008
- To Recognize the Specificity of RD
- To Provide Information for Patients, health professionals and general public
- National Reference Centres (Expertise)
- To Respond to Specific Accompaniment (health/social) Needs of People Living with RD

# Pays de la Loire (Region of the Loire River)

- 3.6 Million Inhabitants
- 5.6 % of the Population of France (65.8 M)
- 180 000 People Living with Rare Disease in this Region



# 180 000 People Living with Rare Disease in Pays de la Loire

- What can we do for them?
- In their Everyday Lives
- In their Close Environment
  - Family
  - Healthcare professionals
  - Social care services
- Regional Partners
- Common thread : Subsidiarity



# The aims of PRIOR

- To Improve Care (Health) Pathway and Life Course
- To Improve the Networking of Professionals (health/social)
- To Improve the Access to financial support, School, Employment
- To Reduce the Waiting Time in Social Cares

# Who is PRIOR For?

- People Living with Rare Disease
- Family Caregivers (“Natural Helpers”)
- Professionals
  - Health care
  - Social care
  - Education
  - Career Guidance
- Patient Organisations

# How does PRIOR work?

- Information : Disseminate and Share Skills and Knowledge
- Guidance : Draw-up an Inventory of (RD) Expertise in Pays de la Loire
- Social Accompaniment : to Support PLWRD in their Life Course
- Organisation of Meetings: to Encourage Exchanges between Health/Social Professionals, Patient Organisations and Families
- Principle of Subsidiarity



# Human and Financial resources

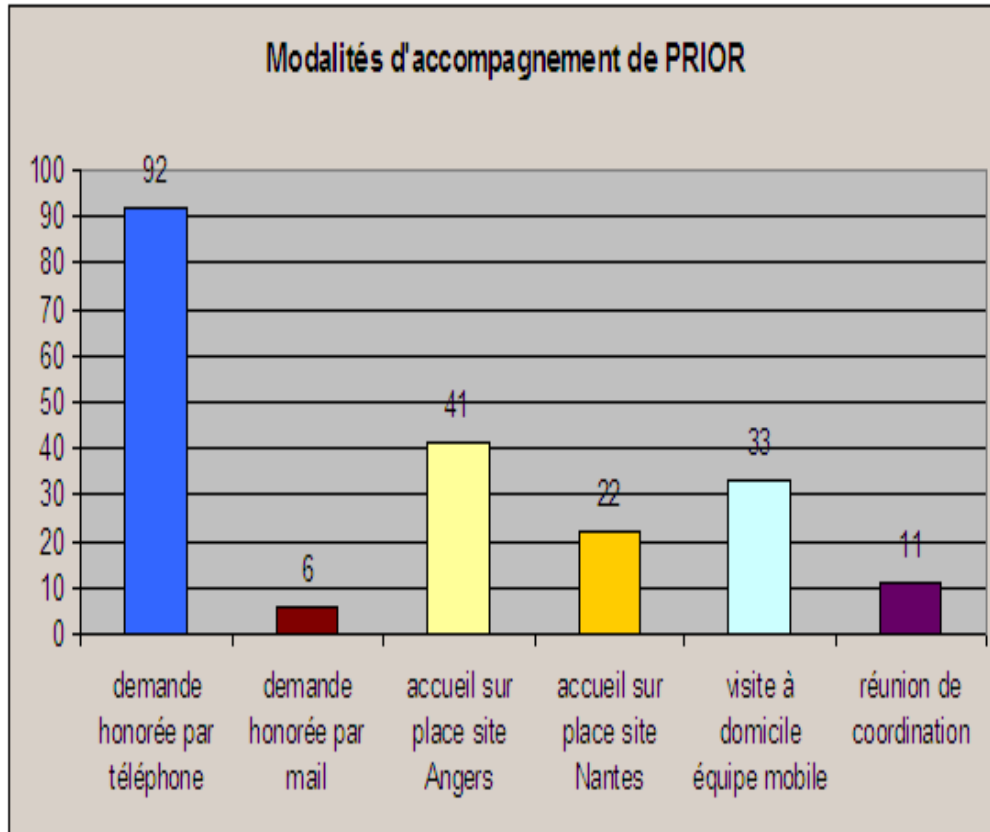
A Multidisciplinary Mobile team :

- Health Manager (1 FTE)
- Genetic Counsellor (0,5 FTE)
- Social worker (1 FTE)
- Psychologist (1,2 FTE)
- Occupational Therapist (0,5 FTE)
- Secretary (2 FTE)
  
- Operating Budget
  - Human Resources (6,2 FTE) : 320 000 € / y
  - operating expenditure : 45 000 € / y

# Results (2010-2014)

- 750 PLWRD have contacted PRIOR
- Numerous categories of requests
- 30 coordination meetings with health/social professionals
- 5 regional conferences
- 850 professionals involved

# 2013

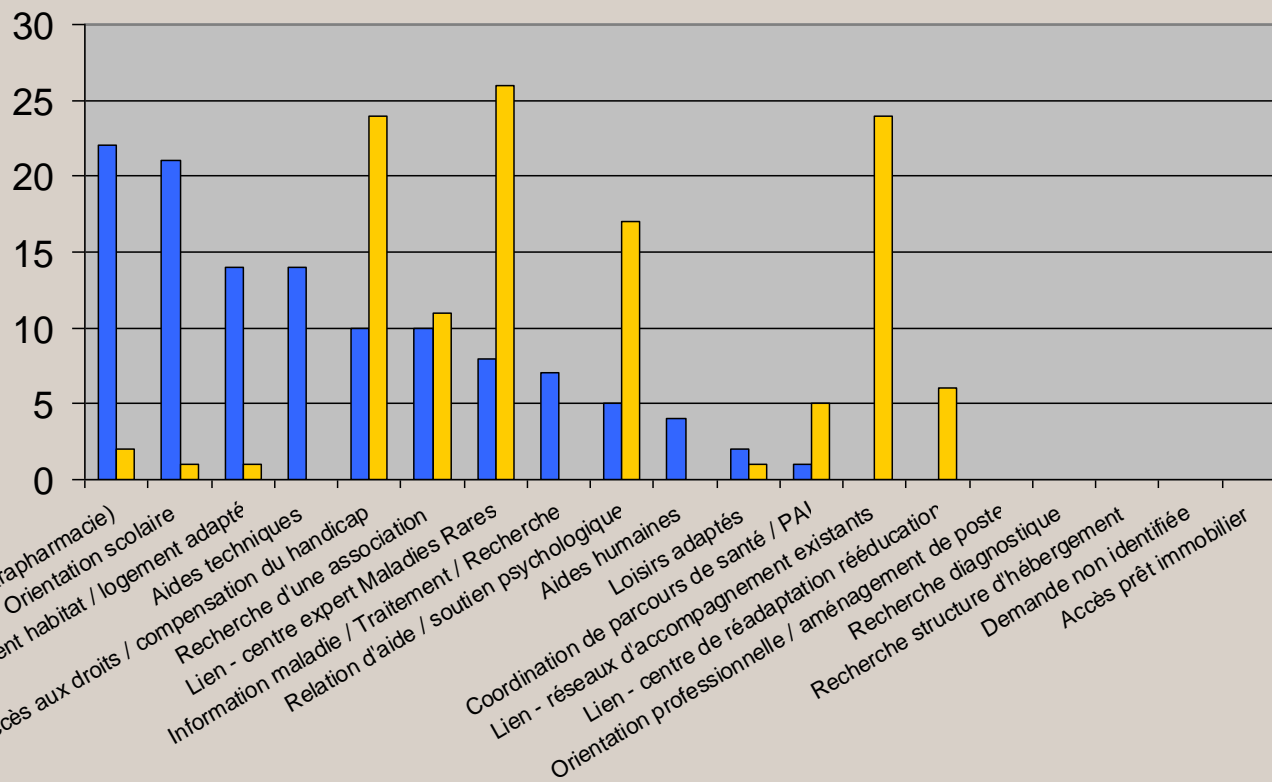


- Phone Calls
- Mails
- Interviews
- Home Visits
- Coordination Meetings

## Demandes et besoins des enfants - 0 à 16 ans

■ Demande exprimée en première intention   
 ■ Action de première intention

Nombre de demandes



**SCHÉMA NATIONAL  
D'ORGANISATION SOCIALE  
ET MÉDICO-SOCIALE POUR  
LES HANDICAPS RARES 2009-2013**



National Solidarity Fund for Autonomy

# Rare Handicaps

1. A severe hearing impairment associated with a severe visual impairment
2. A severe visual impairment associated with other severe deficiencies
3. A severe hearing impairment associated with other severe deficiencies
4. A severe dysphasia associated or not with another deficiency
5. Association of one or more severe deficiencies and a chronic, severe and progressive disorder such as:
  - A mitochondrial dysfunction
  - An inherited disorder of metabolism
  - A progressive disorder of CNS
  - A severe epilepsy
6. Situations most complex

# A National Network of Bridging Teams :

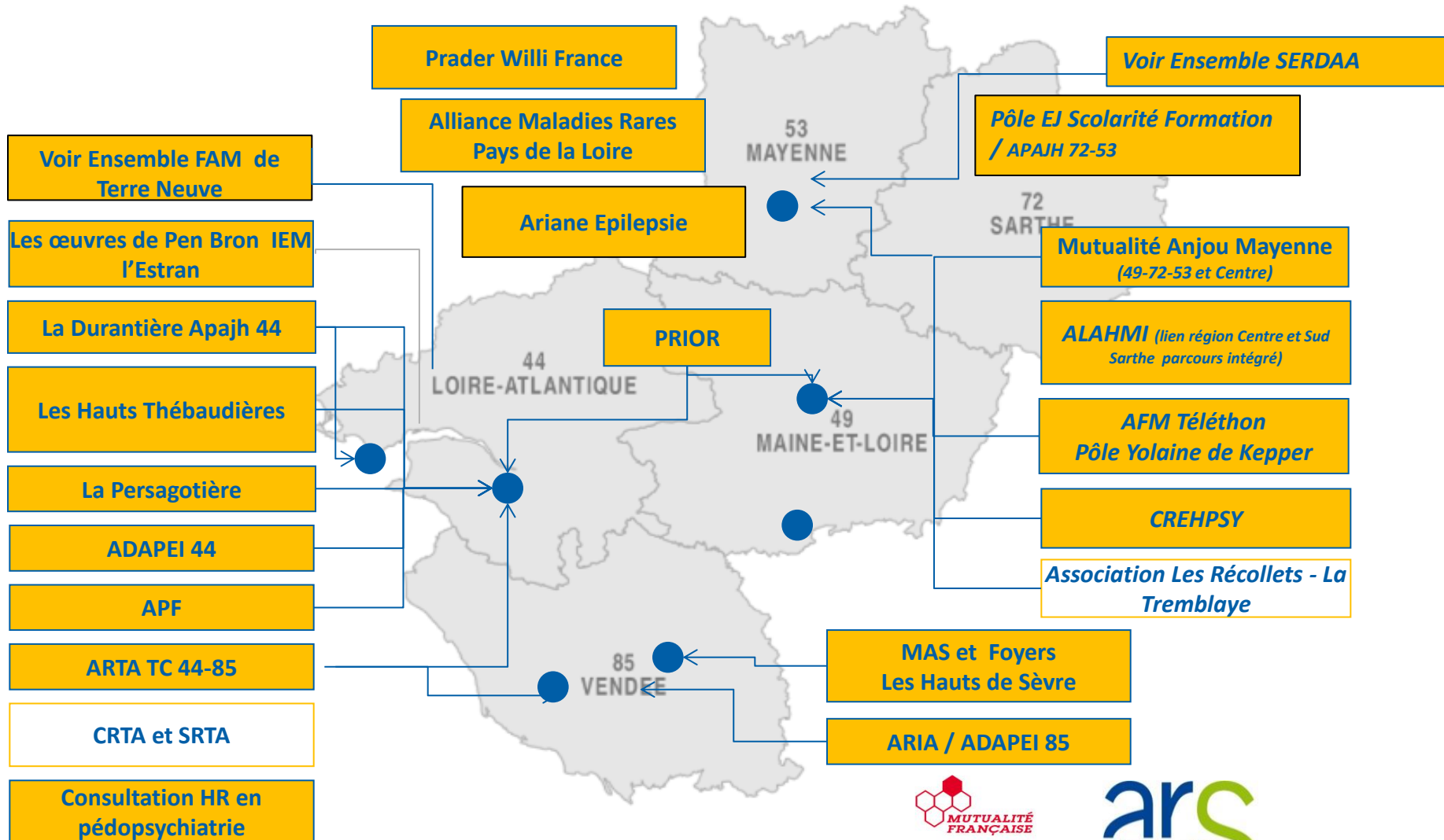
## Pays de la Loire



**DGCS** : Direction Générale de la Cohésion sociale  
**CNSA** : Caisse Nationale Solidarité Autonomie  
**GNCHR** : Groupement National de Coopération Handicaps Rares



# The team involves 23 partners





# Research Projects and New Opportunities

- HuntExpert (Family Expertise in Huntington Diseases)
- ICI Angers : Collective Initiative of (Social) Inclusion
- RD Reference Centre Consortium

# Conclusion

- For RD, the Problem is not the Scarcity of the Disease but the Complexity of the Situation
- Social Problems Should be Dealt with at the Most Immediate Level Consistent with their Solution
- A Regional Network of Competence Both in Health and Social Cares

Thank You For Your Attention  
Any Questions?



**PRIOR - Equipe relais**  
**Maladies Rares – Handicaps Rares**  
**Pays de La Loire**