

# PRORARIS



Alliance Maladies Rares – Suisse  
Allianz Seltener Krankheiten – Schweiz  
Alleanza Malattie Rare – Svizzera

## RARE DISEASES

**Example of coordination :  
Pilot scheme TCC Valais**

*Eurordis workshop Gothenburg  
8-9th September 2016*

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# An XXXtra-ordinary story



# Training

Training in psychology and psychopathology

« ***Accompaniment of persons living with a genetic disease and of their family*** »

Diploma of the Pierre et Marie Curie University  
Faculty of Medicine Pitié-Salpêtrière (Paris)



# Dissertation

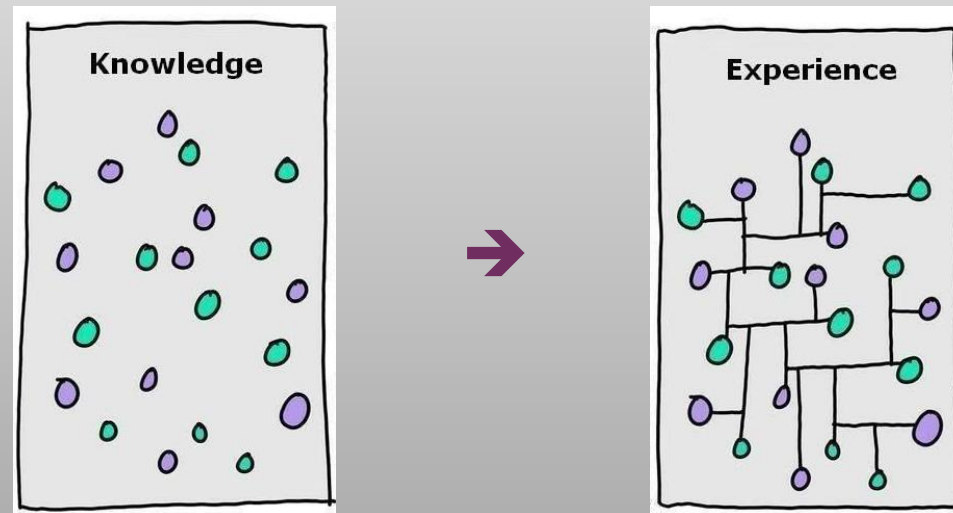
## **Situation, expectation and needs of parents with children affected by a rare genetic disease in the Valais**

Should a new accompaniment be established ?

*Abstract : C. de Kalbermatten, Paediatrica, Vol. 25, No 1, 2014, 24-27  
(in French and in German)*

# Basic premise

- Synergies between professional knowledge and personal experience of the patients (and their relatives)





**TRAINING**

**COACHING**

**COORDINATING**

# Workstreams

- (CONTINUOUS) TRAINING and SENSITIZATION of professionals

*since April 2013*

- COACHING of patients (and their relatives)

*since July 2013*

- Global COORDINATION of the course of the patients (and their relatives)

*since February 2015*

# Intended audience

- Initially :

Families with children and teenagers :

- from 0 to 20 years
- living in the Valais
- affected by a rare disease or
- expecting test results or
- while searching the right diagnosis

- New in 2016 :

- opening of the project for adults



# Why ?

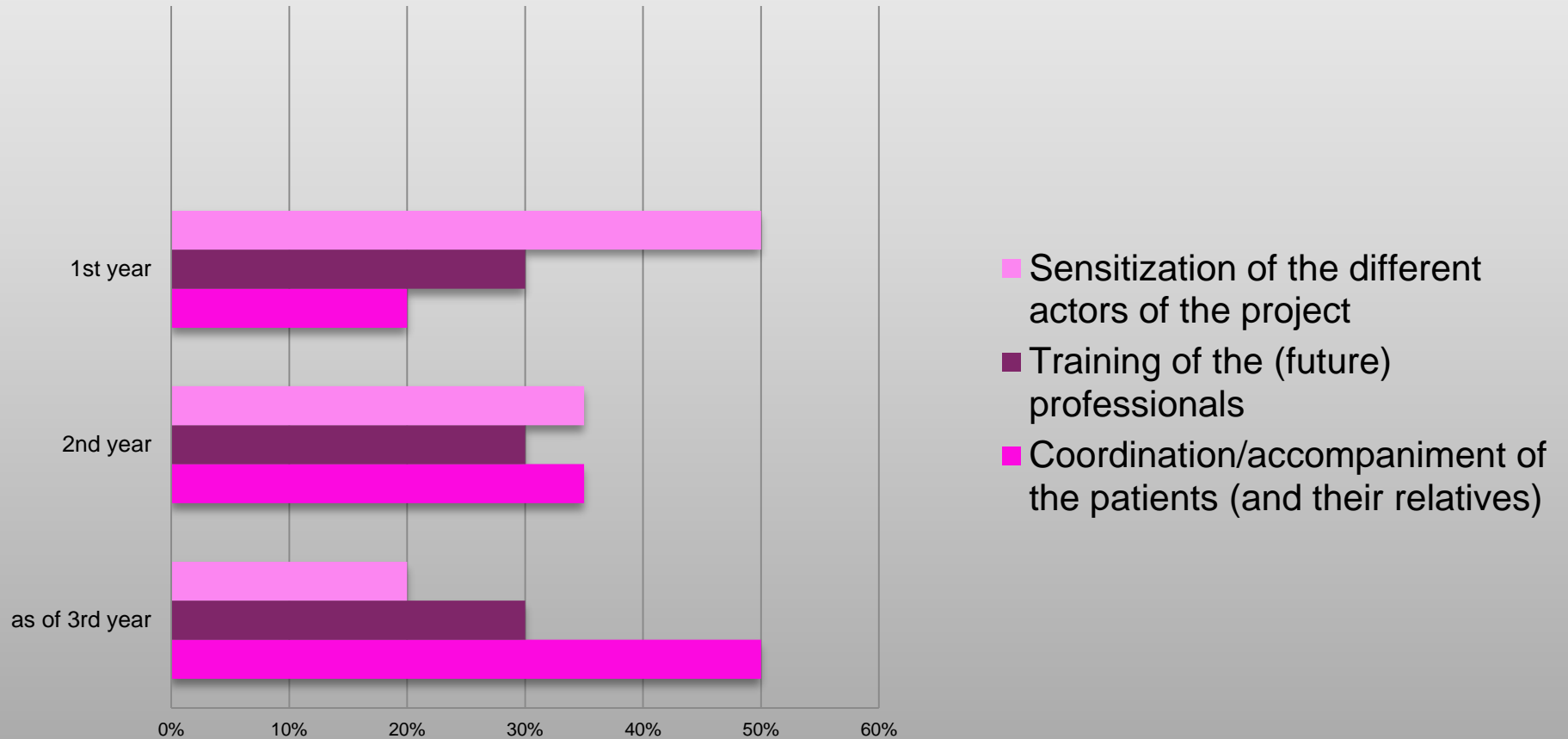
- To support the concerned persons, to know their rights and all appropriate services as well as to how administrations operates (social insurances)
- To burst the isolation problem
- To make exchange possible with other concerned people
- To make the patient's course easier  
→ saving time
- To streamline the costs (adequacy of the assistance)
- To link the professionals

# Main issues

- Patients (and their relatives) :  
added value in terms of support  
→ improving the assistance
- Professionals :  
added value in terms of training and effectiveness  
→ improving the knowledge of the topic  
better sharing of competences  
improving the information flow
- Valais Canton :  
→ pioneering role  
reproducible model (Confederation, Cantons)

# Project duration

1 FTE (100%)



# Conditions of implementation

- Moral guarantee by the Valais Canton :  
Cantonal commission of health promotion
- Organisation :
  - patronage committee :
    - specialized doctors
    - politicians
    - Valais Medical Society
  - work group : significant partners of the health sector (public health, doctors, hospitals, pharmacists, medical-social centres, etc.), of the social and of the (specialized) education sector, of the social insurances, patients, ProRaris

# Identification of the partners

- Handicap social service Emera
- Disability insurance office
- Curative consultation office
- Special pedagogy office
- Public health service
- Social action service
- Valais hospital
- Medical society of Valais
- Paediatric neurologists
- Society of pharmacists of Valais
- Union of Valais health care centres
- Center for development and therapy for children and teenagers (CDTEA)
- Persons concerned

# Function of the partners engaged in the work group

- « Entrance door » to the project :  
information about the project's existence
- Setting up meetings for sensitization/information/training aimed at employees
- Collaboration on the survey of the specific services by each service/institution useful to the patients
- Possible collaboration on network meetings (case management)
- Participation/organisation of information campaigns

# Conditions of implementation (part 2)

- Evaluation of the project, of its functioning and its potential of sustainability
  - University of Fribourg/CH
    - ➔ quantitative dimension (online survey)
  - HES-SO Valais, social work branch
    - ➔ qualitative dimension (focus groups)
  - The methodology is approved by the Cantonal Commission on Medical Ethics Valais (protection and anonymization of datas, document relating free and informed consent, etc.)

# Conditions of implementation (part 2)

- Funding :
  - no public financing
  - ProRaris – Patrouille des Glaciers 2014
  - specific fundraising
  - foundations/associations/  
service clubs/donations/  
miscellaneous
  - an award in 2014 and a distinction in 2015
  - covered : about CHF 475'000.- (= 75% of the initially planned budget)





# Examples of actions

- Sensitization, training and information :
  - basic training : social workers, specialized educators, pharmacy assistants, etc.
  - advanced training : pharmacists, social assistants, paediatrics, specialists in early education, etc.
  - conferences for the general public, for service clubs, etc.
- Accompaniment :
  - tailor-made, according to the needs
  - practical solutions, financial solutions
  - consulting (health insurance, disability insurance, etc.)
  - discussion group for parents and grand-parents, DNA school, etc.

# Examples of actions (part 2)

- Coordination :
  - liaison officer bringing patients into contact with doctors (e.g. geneticists, pain relief centres), social assistants, other associations or discussion groups, other persons concerned, etc.
  - networking with other professionals of the (para)medical or social sector, other associations
- Listening, listening and listening again...
  - benevolent
  - non-judgmental

# Training of the future coordinators

Possible basic trainings	Domains to be enhanced
<ul style="list-style-type: none"><li>- nurses</li><li>- psychologists</li><li>- social workers</li><li>- specialized educators</li><li>- specialized teachers</li><li>- pharmaceutical assistants</li><li>- genetic councillors</li><li>- biologists</li><li>- specialists in early education</li><li>- coordinators for ambulatory medicine</li><li>- etc.</li></ul>	<ul style="list-style-type: none"><li>- genetic</li><li>- pathophysiology</li><li>- psychopathology</li><li>- psychology</li><li>- social insurances</li><li>- case management</li><li>- ethics</li><li>- rare diseases</li><li>- communication</li><li>- training in accompaniment of persons living with a genetic disease and of their family</li><li>- etc.</li></ul>

# Implementation

	Positive factors	Negative factors
CH	<ul style="list-style-type: none"> <li>- national concept since October 2014</li> <li>- principle of coordination found in the concept :               <ul style="list-style-type: none"> <li>• coordinators in hospitals</li> <li>• cantonal coordinators</li> </ul> </li> <li>- considered as a potential model throughout Switzerland by the Federal Office of Public Health (FOPH)</li> </ul>	<ul style="list-style-type: none"> <li>- confederal system of Switzerland</li> <li>- no legal base to make compulsory the application of the measures foreseen by the concept</li> <li>- concept doesn't mention the funding of the measures</li> <li>- rather weak political will</li> </ul>
VS	<ul style="list-style-type: none"> <li>- pilot scheme Valais</li> <li>- good media exposure in the Valais</li> <li>- Valais is a representative canton (population, wealth, bilingualism)</li> </ul>	<ul style="list-style-type: none"> <li>- pilot scheme Valais</li> <li>- weak media exposure outside of the Valais</li> </ul>
	<ul style="list-style-type: none"> <li>- associative project, non official nor institutional</li> </ul>	<ul style="list-style-type: none"> <li>- associative project, non official nor institutional</li> </ul>

# Patient's feedbacks

« Once the diagnosis received, you find yourself all alone in a desert, ... in this project, there are people who understand. »

« Everybody can talk about what's on his mind and his preoccupations, and help others to find tracks for solutions. »

« The diseases are not the same, but the preoccupations are. »

« Here, you meet families with the same experience... we share our fears and scares, but also our tips... a real sunshine in our family life. »

« The project directs to good resources. It helps to reduce the isolation and to go further. » »

# Patient's feedbacks (part 2)

« This project facilitates the access to resources and catalogues them... this is a very good thing. »

« It answers the need for exchanges, to be understood... there is a great solidarity to be felt in the face of all these different diseases. »

« It is reassuring for some parents to discover what can be possible. »

« This project helps us to learn how to put these pieces of puzzle together. »

# Parent's conclusions

- The pilot scheme acts as an entrance door to the complex world of rare diseases.
- It allows to organize the information received.
- It works as a sorter and helps to find the good referral.
- It helps to unblock certain situations.

# On August 31<sup>th</sup> 2016

Planned	Achieved
1 post at 100% (= 1 FTE) for 3 years	1 post at 40% (4 month), then improvement to 50% (7 month), then improvement to 60% as of January 2016, then improvement to 70% since June 2016
1 office for 3 years	Administration work at home, then consultation in an office provided by the hospital since March 2015 Rented office since September 2016
A maximum of 100 patients in 3 years	Contacts with 32 families (= 37 children) 5 adults (1 renunciation)
« Grey zone »	Given response
<ul style="list-style-type: none"> <li>- request of information (2)</li> <li>- patients outside Valais (2)</li> <li>- non rare disease (1)</li> <li>- rare complications of a non rare disease (1)</li> </ul>	<ul style="list-style-type: none"> <li>➔ counsel, orientation over the phone (4)</li> <li>➔ consultations without participation to the project (2)</li> </ul>



# RARE DISEASES

personalized accompaniment by a concerned specialist

**For whom?** All persons living in the Valais with a recent diagnosis of a rare disease, expecting results or even while searching the right diagnosis

**How?** By sensitization, information and training for caring specialists, accompaniment of the concerned patients all along the process and coordination of the different experts' interventions

**What?** A pilot scheme by ProRaris, Alliance for Rare Diseases Switzerland

**Why?** To make life easier for those concerned persons, to enable them to access their rights and discover all appropriate services to facilitate their everyday life, to burst the frequent situation of isolation and to make exchange possible with other concerned people



**TRAINING  
COACHING  
COORDINATING**

**Cost?** ProRaris' fundraising allows to offer free services to the concerned persons during the project scheme period

**When?** By appointment

**Where?** The consultations are held in Sion

## Donations

ProRaris  
Project TCC Valais  
Banque Cantonale du Valais  
IBAN CH60 0076 5001 0234 9290 2

## Contact

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Distinguished by the CSS Foundation award 2014 for the best promotion of social actions in health and accident insurance

Decorated by one of the *mon équilibre* distinctions 2015 (*my balance*), a Migros Culture Percentage project





**You've never actually been on a tiger hunt..have you?**

*Tony*