

## Abstract

Rare disease associations have an essential role in informing patients about the scientific and medical implications of their disease. Moreover, they are increasingly interested in research, from which they hope a better knowledge and prevention of their disease. Because the time scales of research and of patients waiting for treatments intrinsically differ, it is essential to train members of disease associations with the various aspects of research, in order to contribute to a closer relationship between these associations and the scientific community.

Accordingly, the association DNA school in Marseilles (renamed Tous Chercheurs in 2007) has developed practical trainings in molecular biology and genetics for orphan genetic disease associations. These 3-days sessions take place in a laboratory where the trainees work as researchers, under the guidance of experienced tutors. They learn to observe, formulate hypotheses and carry out experiments. In addition to the practical work, each session includes discussions with researchers specialized in the corresponding pathology. The trainees thus understand concretely the work and constraints of researchers.

Since 2004, we have formed 130 patients from very diverse associations, highlighting a strong need for this kind of training. To meet the increasing demand from French associations, we set up in 2007 a transfer of skills to the French-speaking Federation of DNA Schools, thus making the trainings available on a national scale. The trainings met with a similar success at the national level and we are now looking forward to extending them to a European level. With that aim in mind, we are looking for potential European partners (both popular science institutes and genetic disease associations).

The development of this innovative action was made possible by the support of our partners : AFM (Association Française pour les Myopathies), Inserm (Institut de la Recherche Médicale) and CNRS (Centre National de Recherche Scientifique)

## Who we are

Tous Chercheurs is a training center for experiments and debate in biology, created and animated by researchers. We receive students, members of rare disease associations and general public for practical trainings : through observations, questions, elaborations of hypotheses and protocols, trainees experiment, interact, discuss just like researchers do in their everyday work.

Our lab is located in the Inmed center (Institut de Neurobiologie de la Méditerranée, Marseilles, France.

## Biology and functioning of Research made understandable to everyone!

Do you have trouble understanding the time scale of research? Would you like to know precisely what DNA is and unravel its mysteries? *Tous Chercheurs* and the DNA Schools offer you a chance to familiarize yourself with biology, genetics and the world of research, all in an enjoyable setting.

## Aim of our trainings for rare disease associations

Our trainings aim to give you:

- a basis in biology and genetics
- clear explanations on the origin and transmission of genetic diseases
- an understanding of scientific methods and the specificities of research (time scale, ...)

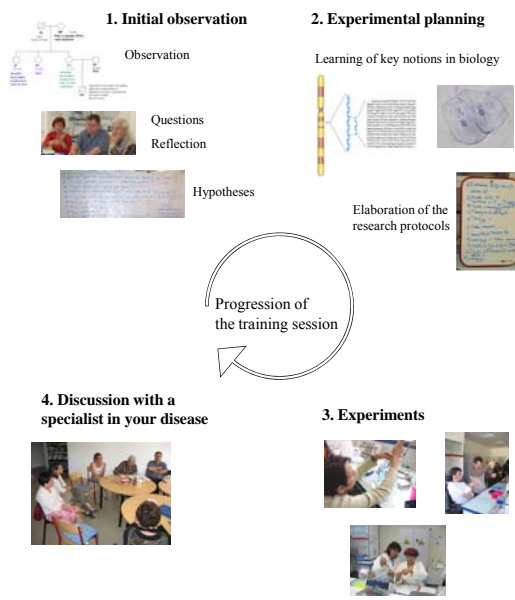
This way we hope to reinforce the dialogue between disease associations, researchers and physicians, an essential factor in medical progress.

## Content of the training

### Put yourself in the skin of a researcher !

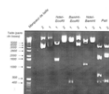
The training, which usually lasts 3 days, is designed to recreate the work of real researchers on a genetic disease :

1. The trainees first study a mock familial genetic consultation. They make observations, analyze them and formulate hypotheses.
2. Then, they learn key concepts of biology, which allow them to propose practical experiments to test their hypotheses.
3. During the next 2 days, they carry out these progressive experiments that acquaint them with core concepts in biology : cells, chromosomes, genes, proteins and illustrate the time scale of research. One experiment is specifically designed to illustrate one key point of research on their disease.
4. The last afternoon is devoted to a free discussion (on research and treatments) between trainees and a researcher specialist in their disease.



## Examples of practical workshops

Identification of mutations in DNA samples



How to create a model system ?

The example of genetically modified bacteria



## Practical information

- Sessions are open to members of genetic disease associations (adults and youngsters  $\geq 15$ )
- In general, each session is devoted to a specific disease or group of diseases
- No prior knowledge of biology is required
- All sites are accessible to the physically impaired
- Free for French-speaking associations

## Associations received since 2004

We have organized 17 training sessions for associations corresponding to very diverse diseases between the start of this project, in March 2004, and December 2007. They are listed below.

Associations received since 2004	Number of sessions	Corresponding disease
- Fédération Huntington Espoir - Huntington France	2	Huntington's disease
Association France Myopathies (AFM)	3	Muscular dystrophies
Groupe FSH de l'Association France Myopathies	1	Facioscapulohumera l muscular dystrophy
Association contre les maladies mitochondriales (AMMI)	1	Mitochondrial diseases
Association contre la maladie de Behçet	1	Behçet's disease
- Association pour la prévention, le traitement et l'étude des polyposes familiales (APTEPF) - Hereditary non polyposis colon cancer (HNPCC)	2	Hereditary colorectal cancers
Association pour l'information et la recherche sur les maladies rénales génétiques (AIRG)	2	Renal genetic diseases
Ligue française contre les dystonies (LFCD-AMADYS)	3	Dystonia
Association française du syndrome de Rett (AFSR)	1	Rett's syndrome
Association contre la maladie de Strümpell-Lorrain	1	Hereditary spastic paraplegia

## Trainees' comments

*"Back to school at this age, is that sensible? The answer is yes, we have spent three terrific days: studious but relaxed, informative but amusing. We left the course, perhaps not more intelligent, but certainly better informed and with our minds more open to the world of research. We recommend this training to whoever wants to be educated and come to understanding. Looking forward to return..."*

Roger Picard, President Fédération Huntington Espoir

*"For the first time I have enjoyed going to school! And now I itch to go back! I have truly appreciated your consideration. I left with plenty of new ideas and hope. Thank you for your sympathy and warm welcome. I have had a wonderful time in which I have learnt a great deal."*

Raphaël Vite, AIRG (renal genetic diseases)

## Transfer of skills to the Federation of French-speaking DNA schools in 2007

DNA schools are popular science institutes with a mission to acquaint a large public with genetics and molecular biology, as well as related medical and social issues. They educate thousands of people a year. The DNA school concept was initiated by the DNA school of Nimes. Since 2007, they are grouped into a federation, to which Tous Chercheurs is affiliated.

In 2007, we organized a transfer of skills to the Federation, thanks to financial support from the French Minister for Research and Technology and from the Association Française contre les Myopathies.

Hence, the trainings are now available at a national level (see map below) : 6 training sessions have already been organized by DNA schools in 2007.



Members of the Federation of French-speaking DNA schools, to which Tous Chercheurs is affiliated

## Conclusion: a call for European partners

We are currently carrying out a survey to determine whether there is an interest in these trainings in other European countries than France.

Our goal is to transfer our skills to other European popular science institutes so that they could organize similar trainings for local genetic disease associations. We will be happy to hear from you if you represent either a popular science institute interested in a transfer of skills, or a genetic disease association with an interest in our trainings.

Setting up them up in your country is likely to take time, however it is very important that we know of your interest.

## Contact information

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