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Press release

Experiencing science in order to better understand their disease

Since 2004, the 'Tous Chercheurs' association, presided over by neurobiologist Constance Hammond (Director of Research of Inserm Unit 901 "Mediterranean Institute of Neurobiology (INMED)"), is offering a novel experience to members of patient groups.

This organisation arranges an average of seven practical training courses in biology per year, each one lasting three days, for people affected by chronic diseases (rare genetic diseases, autoimmune diseases, inflammatory diseases, familial cancers, ...). The details of this programme have just been published in the journal *PLoS Biology* dated 10 February.

These courses enable participants to learn, through practice, the fundamentals of biology necessary to understand their disease; to understand certain known (or supposed) mechanisms at the cause of the disease; and to gain awareness of the specifics and constraints of the research.

The groups are composed of 8 to 12 people, members of the same patient group or of groups affected by similar conditions.

Each session takes place at the Tous Chercheurs laboratory, based at the Mediterranean Institute of Neurobiology (INMED, Inserm), on the Luminy Science Campus (University of the Mediterranean).

Each session runs over three periods:

- The first morning consists of an initial observation period, followed by questioning, which leads to the formulation of a theory of work. This first morning puts the trainee "in the shoes of a researcher" and into an active apprenticeship;
- From the afternoon of the first day to the end of the third morning trainees carry out practical experiments linked to their disease;
- The afternoon of the last day is dedicated to a meeting with a doctor or researcher working on their disease to discuss the latest advances in terms of research or treatment of the disease.

In 10 years, Tous Chercheurs has devised and presented 64 training sessions and as such has trained around 600 members of patient groups.

The prospect for the coming years is to extend this training to other Inserm laboratories. For now, Tous Chercheurs is coordinating training within the French Federation of DNA Schools including four other patient training centres (Angers, Evry-Généthon, Nîmes, Poitiers).

This was made possible thanks to the support of our funding partners, specifically: AFM-Téléthon, Courtin Arthritis Foundation, the PACA (Provence - Alpes - Côte d'Azur) Region, MENESR (French Ministry of National and Higher Education and Research, the town of Marseille, Inserm and Aix-Marseille University.

Among the associations welcomed (and associated diseases), we should note AFM (French Muscular Dystrophy Association - neuromuscular diseases), VLM (Cystic Fibrosis), APTEPF (familial polyposis), AFSR (Rett syndrome), AFAF (Friedreich ataxia), ASL (hereditary spastic paraplegia), Wegener (GPA) and other vasculitis updates, AFA (Crohn's disease and ulcerative colitis), ANDAR (rheumatoid arthritis), AFPCA (relapsing polychondritis), AFDIAG (coeliac disease).

Some of the feedback from trainees who have participated in sessions:

"These three intense, interesting and engaging days have left us "truly wrecked"! *We have gone home very contented and only ask for one thing: to go back, revise, go into depth and still with the same aim: understand better to fight back more! Thank you for what you do, thanks for the autoimmune patient groups and thanks for the patients.* "

Gilbert - French Association for Relapsing Polychondritis

"A very high level course which aimed at bringing it within reach of everyone and from which the full facts of knowledge, hope and desire to live can be retrieved in order to await achievements in research. "

Michel - Waldenstrom Association France

To find out more

www.touschercheurs.fr

Sources

"An innovative lab-based training program to help patient groups understand their disease and the research process"

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To attend the next scheduled course (end of April)

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