

## France Association Française pour la Recherche sur la Trisomie 21



**Internet:** [www.diderotp7.jussieu.fr/AFRT/](http://www.diderotp7.jussieu.fr/AFRT/)

**Founded:** 1990, association law 1902

**President:** Jacqueline London

**Members:** 350

**Finances:** membership fees, donations



**Professor Jacqueline London, who has an adult daughter with Down syndrome, is the President of AFR21**

### Main goals

- to give information on both medical and scientific data in trisomy 21 through the publication "*Nouvelles du chromosome 21*"
- to give funds for research concerning fundamental, clinical and therapeutic aspects as is done for other genetic diseases.

### Services

- counselling
- seminars and courses

### Publications

We publish a regular journal "*Nouvelles du chromosome 21*", two editions per year, 13 issues since 1995.

### Awareness campaign

We have celebrated the 21st March since 2005 with special actions:

- on 21 March 2005 we organised the First National Day for Research on Trisomy 21 "*From the patient to the research: better understanding for better help*" in Paris
- on 21 March 2006 we organised the First World Day for Trisomy 21 in Paris with the conference: "*How to estimate and potentially cure mental retardation*".

### Projects and campaigns

The main project for next year is organising a European congress in March 2007, celebrating World DS Day.

### General information

The main problems in France for people with Down syndrome are:

- Not enough inclusion in schools
- Lack of work opportunities for adults
- Few opportunities for leisure activities

### Numbers

The approximate total number of persons with Down syndrome living in France is 70,000.

### Situation of babies and toddlers under 4 years:

- Medical care insufficient, but cardiac-care is good.
- Physiotherapy and early intervention are not good. Many children have psychomotor therapy on a weekly base.

### Situation of schoolchildren

- about 70% of children up to 6 years are in mainstream kindergarten
- about 60 % of children (6-12 years old) are in mainstream schools
- 5% of children (12-18 years old) are in mainstream secondary schools

Other children go to private schools, homes, special schools or therapy centres.



**The journal *Nouvelles du chromosome 21* is published in French and English**

## European Down Syndrome Association news



### Situation of adults

About 40% of adults up to 35 years old are in employment, but only 20 % of older people. They are mostly in special work places for handicapped people. Only very, very few will have a job in a regular work situation.

Young adults live at home or in special centres, older adults are at home and the very old persons live in institutions.

There are only very few housing facilities where adults with Down syndrome can live independently with only little support.

There are between 5000 to 10,000 persons with Down syndrome over 50 years of age. Not much is known about their situation.