

## Stakes of independence and financing strategies of TRT-5, French advocacy group on therapeutic matters and research (French CAB), 1992-2007

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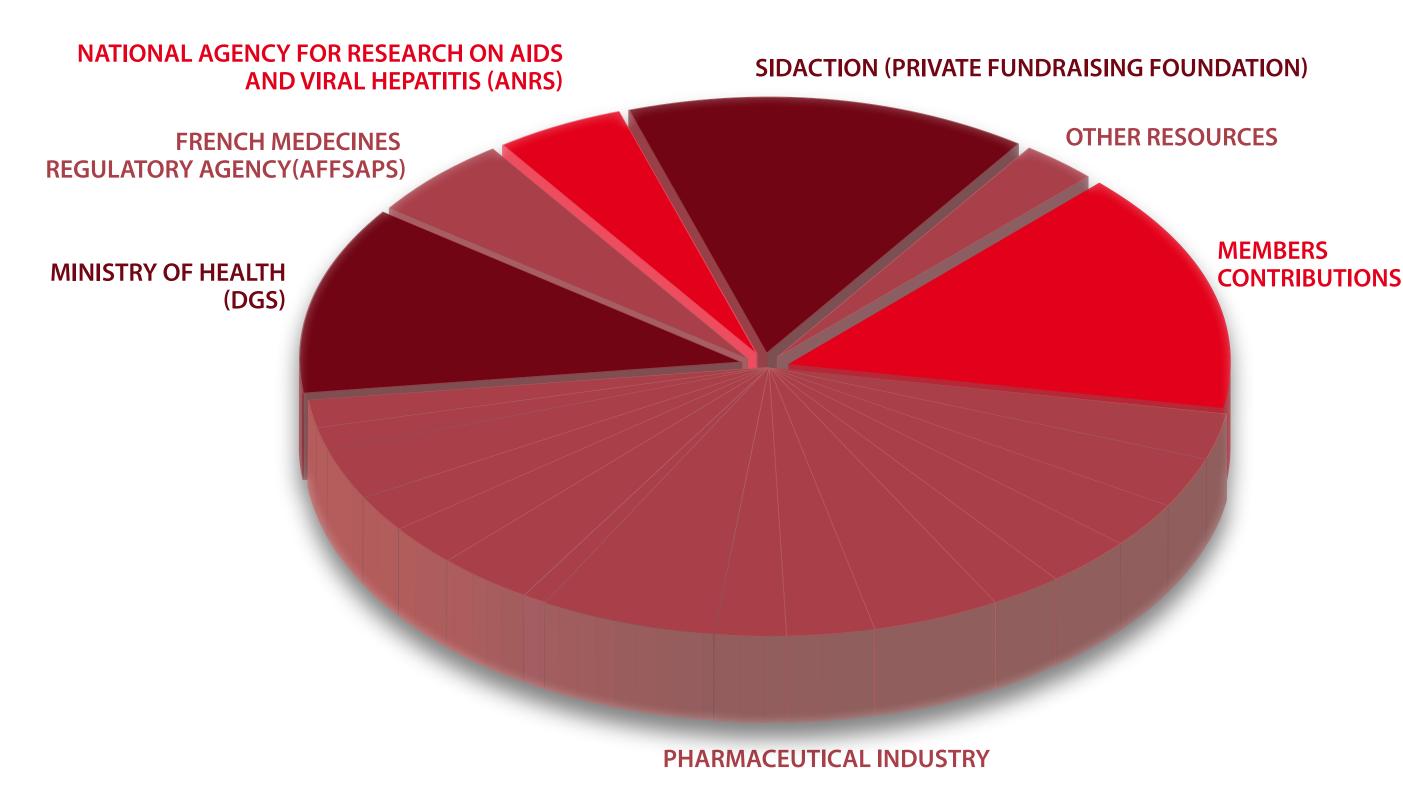
TRT-5 always insures to organize its funding in order to continue his lobby and advocacy actions in total independence. Details and Explanations.

### Issues

To bring the word and expression of the needs of HIV/AIDS affected people and defend their rights and interests in the presence of the other health actors, either public or private, the associations and coalition of associations of people living with HIV/AIDS have to prove their independence. This independence is essential for the credibility and the legitimacy of their actions and claims. It is one of the major pillars of the ethic of an organization of people living with HIV/AIDS and of its statements. It is the condition of the trust of the affected people and, more generally, of the society, in their action.

Because they do not always have incomes generated by their activities, the associations and coalitions of people living with HIV/AIDS constantly seek for the financial support of donors (governmental institutions, foundations, pharmaceutical companies etc.) to carry out their actions. The funding of the associations by the pharmaceutical industry is, for long, source of numerous debates, due to the fact that the industry has evident interests in "controlling" and in "seducing" these actors.

#### The financial resources of TRT-5



TRT-5 budget is based, from many years now, on the subscriptions of its associations, of Sidaction (a private fundraising foundation), of governmental institutions, of public health agencies and of the pharmaceutical industry. The respective ratios of the contributions of these different actors are relatively stable these last years. The ratio of the funds granted by the pharmaceutical industry, has shown an increasing tendency until 2006 where it reached 45, 5% out of the total of the contributions; this ratio represented 42% in 2007 and 41% in 2008. On the basis of these numbers, one can think that TRT-5 depends on the pharmaceutical industry and cannot freely take position on what is his area of competency. We wish to demonstrate that this is not the case.

### Does the TRT-5 depend on the pharmaceutical industry?

In the year 2008, the 41% of the TRT-5 budget which comes from the pharmaceutical industry is granted by 13 different laboratories. The average contribution of each laboratory is about 6 153 €, with a range from 3000 to 9000 €. If one laboratory decided to keep the TRT-5 from his contribution as a "reprimand", the prejudice will not compromise the existence of the TRT-5.

Due to this, the TRT-5 is able to express, whenever necessary, public positions to denounce the unacceptable attitudes of laboratories. During these last years, the TRT-5 has notably opposed:

- to Roche on the precocious access to enfuvirtide (Fuzeon®), on the disposal of an alternative administration method to the "classical injection needles" of the Fuzeon® (Biojector 2000®), or either on the contamination of the Viracept® (nelfinavir) by the Ethyl mesylate;

- to Boehringer Ingelheim on the precocious access to tipranavir (Aptivus®); - to Bristol-Myers Squibb on the matter of the adverse effects of his (Zerit®, Sustiva®) treatments or on the stop of the production of the 100mg formula of the
- Sustiva®; - to Pfizer, Schering-Plough and GlaxoSmithKline on the anti-CCR5 affair;
- to Abbott on the development of a meltrex Norvir® (said to be a «dry formula»), on the restrictions on the access to Kaletra® in Thailand and on the complaint against Act Up-Paris.

The associative actors are one of the rare anti-establishment force facing up the pharmaceutical industry: no regulation agency nor the medical profession cannot address at such radical length as the associations facing up the pharmaceutical industry. The associative actors only can have the legitimacy to defend the word and the interest of affected people, with no other consideration.

# The conditions of independency of the associations of people living with HIV/AIDS

and the trust that is placed in them

One of the ways for the associations and coalitions of associations of people living with HIV/AIDS to preserve the independency of their address is to increase the sources of funding in such a way that the contribution of every donor to their global budget might be reduced and easily made up in decreasing expenditures or increasing another grant post.

The fact of receiving funds from the pharmaceutical industry also guarantees the independency of the associations and coalitions towards public institutions or towards the other private actors. To develop and keep its financial stability, the TRT-5 has to increase its resources as a whole. We refuse easy but ethically problematic options that the pharmaceutical industry can offer the representatives of the affected people. We are either planning to increase public grants, to obtain support from private foundations or to have some specific projects financed, like our engagement for women.

TRT-5 bases its ethic on financial resources on two main thrusts: diversity of donors and transparency which is a prerequisite to attest the credibility and the honesty of its associative proceeding. TRT-5 joins itself to the calls to financial transparency for all the associative actors in the field of health, whatever their actions and the sources of their resources may be.

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What is TRT-5?

















www.trt-5.org

TRT-5 (Traitements & Recherche Thérapeutique 5) is a coalition of eight French HIV/AIDS organisations, both community-based and services, working on access to best standard of care and on HIV & Aids clinical researcth: Act Up-Paris, Actions Traitements, AIDES, Arcat, Dessine Moi un Mouton, Nova Dona, Sida Info Service and Sol en Si.

TRT-5 was founded in 1992 by five HIV/AIDS organisations in the context of a medical and treatment emergency situation for people with HIV and AIDS. Its objectives are to promote the needs of PLHAs and advocate on their behalf in the areas of clinical research, standard of care, governmental institutions and the pharmaceutical industry, and to facilitate the dissemination amongst PLHAs of accurate and up to date information on treatments and clinical research results through its network and the organisation of a yearly symposium that focuses on a single high priority issue.