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TRT_5

Technical advocacy on treatment and research: a man's world?

The example of the TRT-5 : the French Community Advisory Board (CAB) on AIDS Treatments.

TRT-5 women working group

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Are the health needs of women adequately addressed by medical research as it is currently conducted?

In France today, women account for 42% of new HIV infections, but only less than 20% of participants in most clinical trials. Questions about inclusion and exclusion in trials have long been centred on women as mothers (mother to child transmission / protection of a potential foetus) and not on women themselves.

There is a lack of sex specific questions and analysis of data in the design of most medical research endeavours. Matters relating specifically to sex and the distinctive characteristics of infection among women are not well assimilated in trial protocols.

Founded in 1992, TRT-5 brings together French HIV NGOs to relay the needs of communities affected by HIV to medical researchers and clinicians. Our coalition only recently integrated women's issues as a priority. TRT-5 brings to the forefront medical and scientific justifications which complement advocacy work that addresses women's risks and vulnerabilities to HIV in terms of human rights.

Our action in medical research: what do we do?

The arrival of several women activists from the member NGOs "AIDES" and "Sol en Si" led the TRT-5 to create in 2007 a working group on women needs in terms of research.

The group uses the TRT-5 network and advocacy experience to call upon the French national research agency on AIDS and hepatitis (ANRS) and related stakeholders :

- to increase women's access to trials,
- to place greater emphasis upon gender issues in clinical studies (To improve our knowledge of women's health and detect significant sex differences, we need appropriate analysis of data by sex and specific questions),
- to streamline gender considerations in the updated French guidelines for HIV care.

Understanding medical research: what have we learned so far?

- Women are biologically different so it is scientifically pertinent to enrol them in adequate numbers to provide answers relevant to them.
- Getting treatments and prevention strategies adapted to women requires multidisciplinary responses.
- It is difficult but possible to bring together treatment advocates and women rights activists.
- The inclusion of women issues in the TRT-5's agenda is essential for visibility to health institutions, researchers and to the pharmaceutical industry.

What are the next steps on the TRT-5 agenda in term of women in medical research ?

- To produce a charter calling for adequate representation of women in clinical research and for data to be analysed in terms of gender.
- To call for studies in social sciences to find solutions to encourage greater participation by women in trials.
- Organise a conference on women in research.

By adding scientific arguments that strengthen advocacy for women's health, we become able to speak the same language as clinicians, researcher and trial designers. If we want to bring about changes in research, we need to have a place among coalitions that are recognized as pertinent on the field.

Are we talking about a "women only" initiative? No, the discovery of differences between male and female response to disease and treatments has implications for both genders in clinical practice, disease prevention and care, and medical education.

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What is TRT-5?

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.

www.trt-5.org