

# Patients Involved | Case Report

## HIV patients and Janssen R&D collaboration

This is a collaboration of a pharmaceutical manufacturer (Janssen R&D) with the patient's organisation European AIDS Treatment Group – European Liver Patients Association (EATG – ELPA – Treatment action group).

Patients were involved as follows:

- Protocol design and review.
- Informed consent form (ICF) review.
- Participation in Drug Safety Monitoring Board (DSMB).

- Participation in Investigator Meeting.
- Building capacity in the area of Health Economics.

Janssen initiated also a collaboration with the London School of Economics and a tailor-made educational program was constructed for the EATG members. Afterwards, the course was handed over for further capacity building within their organisation without further company involvement.



## Who was involved?

Janssen, EATG, ELPA, Treatment Action Group

## Level of patient expertise

- Patients/parents with personal disease experience.
- Expert patient/patient advocate with good expertise on disease, but little R&D experience.
- Expert patient/patient advocate with good expertise on disease and good R&D experience.

## Benefits

- Thanks to this collaboration we obtained:
- More targeted development.
- Better understanding of real needs for research and development.
- Faster study enrolment.
- Closer contacts between R&D experts and beneficiaries (motivational benefit).
- Better outcomes for patients.

## Challenges

In disease areas outside HIV, professors and experts not always in favour of having patients on board.

We have discussed with them and showed EATG success example as model.

## Learnings

- Need to structure the process to ensure continuing process beyond individuals.
- Patient literacy needs to be ensured to optimise feedback.
- Ability to replicate this collaboration across more patient groups and advocates to increase knowledge on different topics, amongst other, Health Economics.

