

# **Ageing with HIV Conference**

**“New challenges and unmet needs of people living with HIV/AIDS aged 50+”**

**EATG**

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**Maxime Journiac**

# Personal elements of my biography

- 62 years old gay man
- Widower at the age of 32
- Living with HIV & HBV for 35 years
- Living with HCV for over 40 years
  - ✓ Virologically cured for 18 months
  - ✓ Cirrhosis still affecting my liver
- Diagnosed with PAH in 2004

# HIV Biography

- Never developed full blown AIDS
- Class B CDC events
- CD 4 nadir 212
- First AZT pill Dec 1988 in a clinical trial
- 3 clinical trials
- 6 different HIV treatments
- 7 HCV treatment courses
- One severe drug-drug interaction in 2011

# Limits of my talk

- subjective observations
- Personal experiences
- Mythical “universal us” that does not really exist

# To be living and ageing with HIV

- Not easy
- Can be challenging
- Can be a Blessing and a Curse
  - Many got infected 25-30 years ago or longer
  - Never thought we'd see the new century or reached 50
  - Many adverse events
- To be alive today is a victory and a blessing

# Revisiting History

- Early days no test people where dying from OIs
- Late 80's mid 90's better OIs' prevention
- 1985 first HIV tests
- 1986 first clinical trials: AZT followed by others
- Late 80's early 90's many alternative therapies
- 1992 Long Term Survivors concept
- 1996 arrival HAART
- Lazarus Syndrome

# Curse or High price to be paid (1)

- Many adverse events:
  - ✓ Chronic fatigue
  - ✓ Poor energy
  - ✓ Neuro-cognitive impairments
  - ✓ Premature ageing
  - ✓ Multiple co-morbidities
  - ✓ Organ failure

# High price to be paid (2)

- Stigmatization & discrimination
  - Self exclusion and isolation
  - Withdrawal from social, emotional and sexual life
- Survivor's guilt
- Psychological impact of a life long treatment :
  - Daily reminder of our condition
  - No forgiveness, no drugs holiday
- Economical impact
  - Social minima
  - Shortened careers
  - impact on retirement pensions
- Loss of physical and/or neurological autonomy
  - What is planned in terms of specific services, specialised housing, retiring homes, etc.?



# “Bereavement of the Bereavement”

- With the arrival of HAART
  - Less deaths
- Doctors, Physicians and Society told us
  - “Go beyond your bereavement” “Go on living” “Resume your life”,...
- Not easy to do
  - Destabilization
  - Difficulty to adjust to the new paradigm

# Lessons to be learned

- Learn to live with a possible future
- Live and enjoy moments of well being and happiness
- Accept the limitations that go with living and ageing with HIV
- Strong sense of resilience

# Where do we stand?

- Going back and forth from the joy to be still alive and the tiredness to live with fears and uncertainties.
- Going through fear and happiness, depending on what is happening to us physically, socially and psychologically at a given moment.
- Staggering from pessimism to optimism: mentally and emotionally exhausting.
- Feeling like riding an emotional roller-coaster

# My Final Thoughts

- The true challenge of living and ageing with HIV: Yes to life but at what cost and under which conditions?
- It is up to us PLWH, activists, researchers, physicians, pharmaceutical companies and politicians to make sure that the needs of ageing PLWH are addressed and that answers and solutions are found and implemented.



Act-Up New York Target City Hall, March 1991