



European Men's Health Forum (EMHF)  
Rue Wiertz 50/28, 1050 Brussels, Belgium  
Registered A.I.S.B.L 15747/2002  
[www.emhf.org](http://www.emhf.org)

## Press Release

### **European Men's Health Forum Announces Interim Results of Quality of Life Study for People Living with HIV**

Preliminary data from 'European HIV-Related Quality of Life Review' suggests significant differences between male and female perceptions of living with HIV

**London, UK, 8 December 2004;** Concerns about treatment, work and social life, and effects of discrimination continue to be major worries for men and women living with HIV. This is according to the pilot phase results of a pan-European study '*European HIV-related Quality of Life Review*', developed by the European Men's Health Forum (EMHF).

A comprehensive online English language questionnaire of over 50 compound questions between September and October 2004 was proposed to HIV-diagnosed adults residing throughout Europe and examined medical and healthcare factors, physical and emotional well-being, economic and social support and overall quality of life. Results from nearly 300 respondents were collated and analysed.

Only 70% of respondents declared themselves 'satisfied' or 'very satisfied' with the quality of their life, suggesting that while advances have been made to improve their overall experience, they still need to see improvements in the areas of treatment, emotional as well as physical well-being.

The interim report indicates that the extent of such expectations vary significantly according to gender. The effectiveness of future measures aimed at improving the quality of life of HIV positive people may more than ever depend on the respect of such differences.

The study was initiated in mid 2004 and was aimed at examining expectations of men and women living with HIV towards quality of life and the effect of gender-based factors. The questionnaire was made available through the website of the EMHF. A number of global and international websites publicised the existence of the study and posted links from their site to the EMHF site.

Whilst most respondents started treatment within one year of diagnosis, almost 40% did not for at least 2 years. Nearly 20% of those currently not on treatment stated that they felt that the potential side effects deterred them from taking medication. 23% of patients stated that they did not see why they should start treatment, as they felt fine.

For those people taking medication, most felt that overall, their treatment was effective at controlling the disease. They indicated that fewer pills per day and the reduction of medication side effects were the main factors that improved their experience of drug regimens. 47% stated that they had been on 2 to 3 drug regimens so far.

#### **Key findings of pilot phase**

- 40% respondents stated that they thought about their status most or all the time, but their experience of psycho-social factors appears to be largely influenced by gender
- Men reported little loneliness or low libido. Women, on the other hand, seemed particularly affected by the same aspects and also by anxiety and depression.
- Men expressed a higher degree of satisfaction than women in all areas except treatment where they regarded improvement of side effects as the number 1 area for improvement of their quality of life.
- Women declared experiencing a deterioration of their economic status, sense of identity and sense of purpose.
- A reduction of HIV-related discrimination also featured highly on women's list of areas that could improve their quality of life.

Erick Savoye, Director of the European Men's Health Forum said, "Many people living with HIV revealed real concerns with several aspects of their quality of life. These interim results provide some very interesting illustrations of the issues foremost in the minds of HIV positive individuals. A gender-based interpretation of these concerns can be very complex and we hope to be able to draw stronger and more precise conclusions when we publish the results of the second phase of this study in the second quarter of 2005."

The EMHF has received the support of HIV patients' organisations in France, Germany, Italy and Spain to publicise the existence of the study and disseminate questionnaires in their native language. In addition, the UK Multi-centre Research

and Ethics Committee (MREC) has granted the EMHF approval to offer the survey to patients visiting British HIV treatment centres.

The study is supported by an unrestricted educational grant from Bristol-Myers Squibb and falls under the umbrella of the One vision European Photographic Competition, designed to reduce HIV-related stigma in Europe.

###

#### **Notes to Editors:**

53% of all respondents to the questionnaire were gay (78% were men) and 33% were heterosexual (of which 92% were women.)

Approximately half of all respondents had been diagnosed since 2000. Over one third indicated that their diagnosis occurred within a year of infection, which for 86% of respondents was through unprotected sex.

81% of responders recorded their ethnic background as West European with a further 14% being African. Approximately two thirds of respondents (67%) were male and 33% female.

Responses were collected by EMHF. The data were analysed on behalf of EMHF by Leeds Metropolitan University, School of Health and Community Care, which produced the interim results.

#### **European Men's Health Forum**

The EMHF is an independent, non-governmental, non-profit-making organisation established to promote male health across Europe. It is a membership organisation managed by a Board of Directors and an executive committee, which represent the diversity of its stakeholders. These include national men's health organisations, EU policy makers, organisations representing health professionals, academics, and women's health and patients' organisations. [www.emhf.org](http://www.emhf.org)

#### **Bristol-Myers Squibb Ltd.**

Bristol-Myers Squibb is a global pharmaceutical and related health care products company whose mission is to extend and enhance human life. [www.bms.com](http://www.bms.com)

#### **One Vision**

For more information about the One Vision campaign, visit [www.onevision2005.org](http://www.onevision2005.org)

#### ***For media enquiries, please contact:***

##### ***Erick Savoye***

Director  
European Men's Health Forum  
Tel: +32 2 401 6188  
Mob: +44 7949 124 975

##### ***Nii Turkson***

Consultant  
Ruder Finn UK Ltd  
Tel: +44 20 7462 8900  
Mail: [nturkson@ruderfinn.co.uk](mailto:nturkson@ruderfinn.co.uk)