

# Haemophilia News: The Use of Social Networks to Inform Patients with Hemophilia

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## INTRODUCTION

Therapies for hemophilia A, B and von Willebrand disease will undergo great changes in the future. A wide range of biosimilars, recombinant coagulation factors with a longer half life, and factors produced by transgenic animals are in development or in clinical trials and will be on the market in the coming years<sup>1-2</sup>. There are reports of successful gene therapies of hemophilia B and promising preclinical research in hemophilia A<sup>3</sup>.

New compounds are currently either being tested for the treatment of hepatitis C or are already launched<sup>4</sup>. More patients with hemophilia are getting access to diagnosis and therapy worldwide. Therefore, a large demand for information about these new developments exists among patients, their relatives and physicians. Patients want to be informed about publications regarding their disease e.g. new treatment options, side effects of therapies, social impact, etc. Only well informed patients can be competent partners with their doctors, health insurances and politicians.

## METHODS

Today, social networks are a source of information for millions of people. One of the most popular networks is Facebook. Young people in particular use this medium to learn for themselves and to share information<sup>5</sup>.

Until recently no website has existed that published only news about hemophilia. Therefore, the Facebook page Haemophilia News (<https://www.facebook.com/HaemophiliaNews>) has been developed. The site is independent from any hemophilia society or pharmaceutical company. It was designed as an additional resource to already existing hemophilia websites, e.g. the World Federation of Hemophilia and various national hemophilia organizations. The goal of this page is to provide information about the development of new treatment options and clotting factors, hepatitis A, B, C, HIV, emerging and re-emerging pathogens, and the supply of treatment available in different countries.

The page was launched in July 2012 by Uwe Schlenkrich, MD who is responsible for the content. The sources of information for the page include the following newsletters:

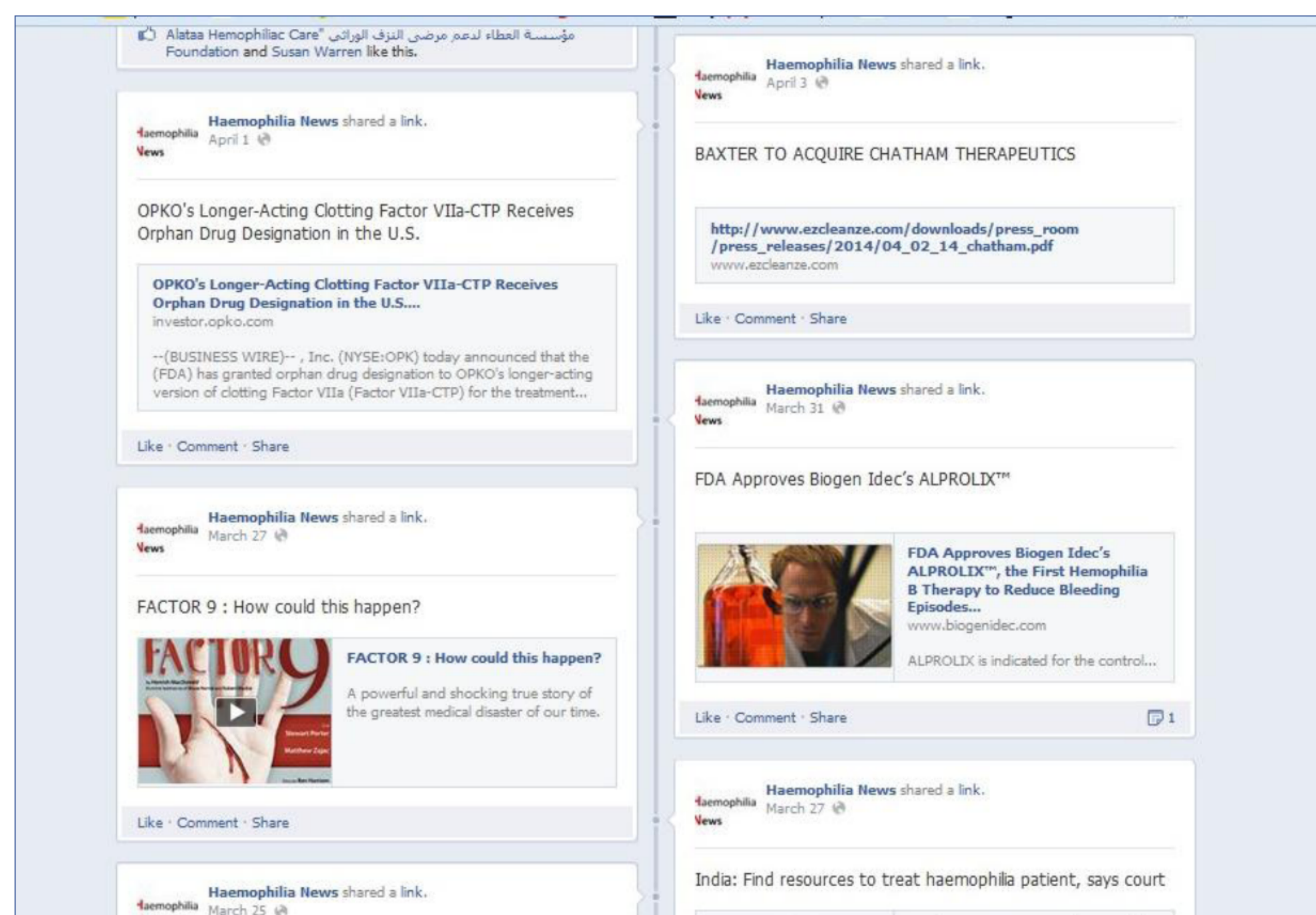
- <http://www.aabbsmartbrief.com>
  - <http://hepatitisnewdrugs.blogspot.de/>
  - <http://www.medpagetoday.com>
  - <http://www.cdc.gov/mmwr/>
- As well as:
- Press releases of companies and societies
  - Daily search for hemophilia on the internet
  - Search for hemophilia in pubmed <http://www.ncbi.nlm.nih.gov/pubmed>

## RESULTS

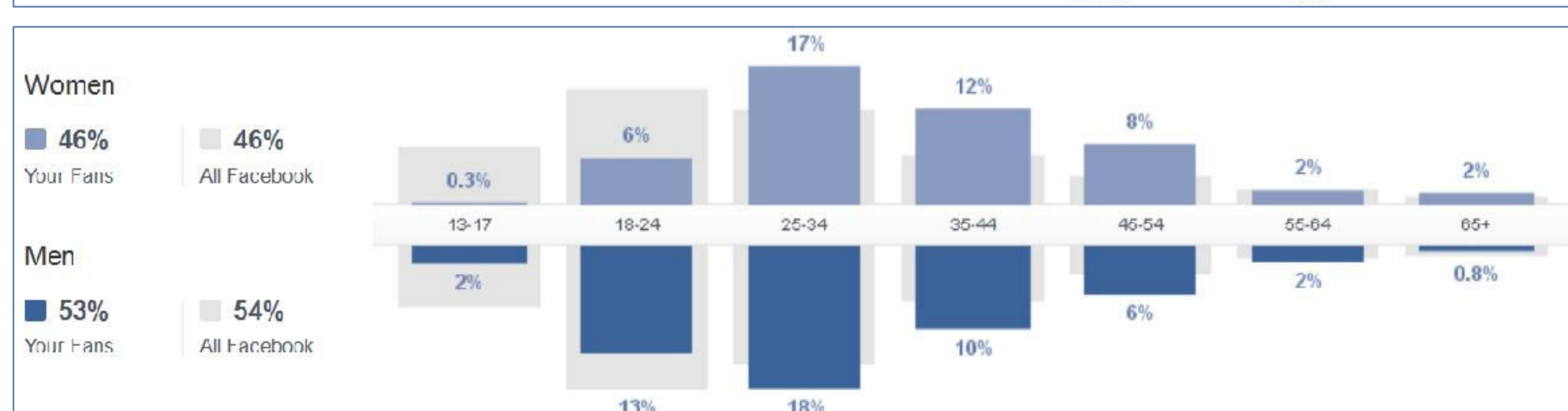
Over 390 people "like" the page so far. The numbers of visitors are between 100 and 500 per week. Most of the users are aged between 18 and 44 years old (78%) and 46% of the users are women with 53% men. Almost half the people that "like" the website are women, which is surprising as hemophilia is more commonly seen as a male disease. It is assumed that young mothers and partners of people with hemophilia are looking for information.

Geographically, most users are located in the USA, India, Germany, United Kingdom and Australia.

Also, national organizations are using the information on the Haemophilia News page to improve the quality of their own websites. This was already performed by the German Haemophilia Society, the European Haemophilia Consortium and the European Haemophilia Network (EUHANET).



## Haemophilia News



### Subjects of Haemophilia News have been:

- New developments of factor VIIa, IX, VIII and XIII
- Failures in the development of recombinant clotting factors
- Clotting factors produced by transgenic animals
- Gene therapy: hemophilia A and B
- RNAi (RNA interference)
- Rare diseases and orphan drugs
- Emerging pathogens
- Infection of people with hemophilia with HIV and HCV
- HCV therapy, new developments, guidelines for therapy, HCV and sexual transmission
- HCV and alcohol
- HIV therapy
- Hepatocellular carcinoma
- HBV therapy, new developments
- Contamination of blood products
- The situation of people with hemophilia in developing countries
- Sanctions on Iran; effects on patients
- Cuts of supply of clotting factors in Europe
- PID and sex determination of embryos
- Recommended vaccinations for children and adults
- Hemophilia and inhibitors
- Circumcision
- HTA and hemophilia
- Blood test for vCJD
- Treatment cost for hemophilia

## CONCLUSIONS

There is a large demand for information about all aspects of hemophilia. The goal of the Haemophilia News project is to collect and publish news regarding hemophilia. This is done by using the social network Facebook. Over 390 people "like" the page so far. The numbers of visitors are between 100 -and 500 per week. Most of the users are between 18 and 44 years old (77%), with 43% of them women and 56% men.

## REFERENCES

- <sup>1</sup>Peyvandi F, Garagiola I, Seregni S. Future of coagulation factor replacement therapy. *J Thromb Haemost.* June 2013;11(Suppl.1):84-988.
- <sup>2</sup>Lillicrap D. Translational medicine advances in von Willebrand disease. *J Thromb Haemost* 2013; 11 (Suppl.1): 84-98.
- <sup>3</sup>Chuah MK, Evens H, Vandendriessche T. Gene therapy for hemophilia. *J Thromb Haemost.* 2013 Jun;11 (Suppl.1): 99-110.
- <sup>4</sup>Dabbouseh NM, Jensen DM. Future therapies for chronic hepatitis C. *Nat Rev Gastroenterol Hepatol.* 2013 May;10(5):268-76
- <sup>5</sup><http://www.internetworldstats.com/facebook.htm>.

