

# Connecting Patients with Experts: HTLV Social Media



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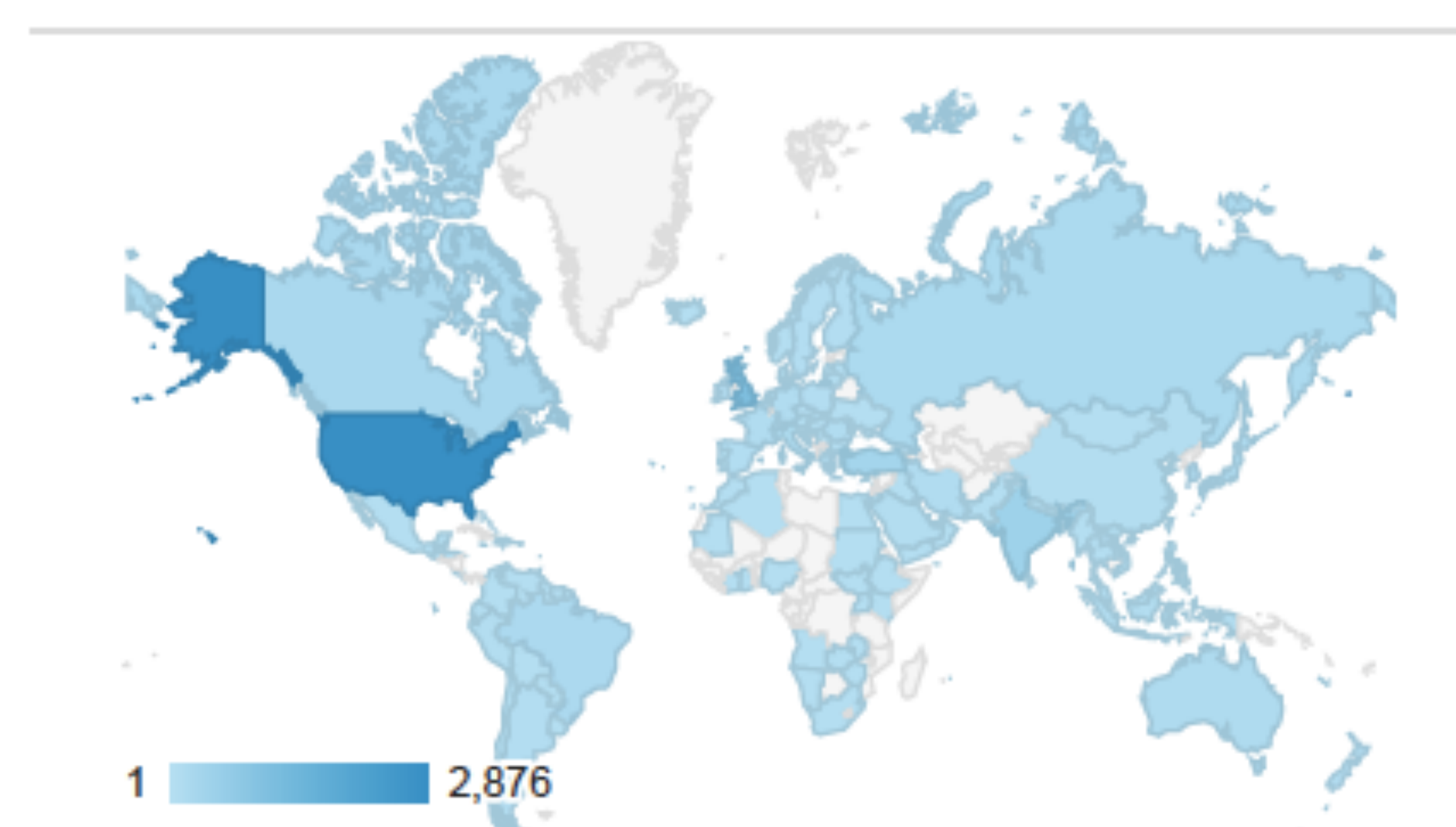
**Background:** The general population, scientist and clinicians are often unaware of HTLV. This is particularly problematic for newly diagnosed patients. HTLV can be transmitted through close contact with body fluids that carry HTLV infected T lymphocytes; and can be transmitted through unprotected sexual intercourse, breastfeeding, used needles, blood transfusions and organ transplantations. Carriers can fear stigmatisation if they enquire about this virus openly and often turn to social media for education and support. Following patient demand [www.HTLVaware.com](http://www.HTLVaware.com), a patient blog, Facebook page and @HTLVaware Twitter account were set up in 2013 to provide patient friendly, accurate HTLV healthcare information. Here we report user frequency of the social media, its applications and patients' feedback.

**Methods:** [www.HTLVaware.com](http://www.HTLVaware.com) Google analysis from 20 Oct 2013 to 26 Feb 2017 and 6 Feb 2016 to 6 Feb 2017. Outcome variables were: users' by country, continent, months, tweets, followers, patient emails. Data are anonymised.

**Results:** 2013-2017: **25,443** web-users, **6,508** Twitter followers, **1,661** Tweets sent. 2016/17: **5,896** web-users.

**Map 1:** Web-users' geographical distribution

Unique Events



**Table 1:** Visits by Country/Territory

Country	Sessions
United States	2,876
United Kingdom	1,085
India	429
Turkey	327
Canada	216
Brazil	163
Russia	158
Italy	117
(not set)	116
Australia	102

**Table 2:** HTLV infection status and route of contact.

	Users
<b>Total</b>	42
<b>Diagnosis</b>	
HTLV negative	18
HTLV-1	15
HTLV-2	1
HTLV indeterminate	4
HAM/TSP	3
ATLL	1
<b>Routes of Contact</b>	
Website	37
Blog	2
Facebook	1
Twitter	1

**Table 3:** Enquiries by HTLVaware web-users and actions taken by HTLVaware team.

	Users
<b>Queries</b>	
Needing Specialist Referral	14
Exposure Risk	19
Information	6
Reassurance	42
<b>Outcomes</b>	
Referred to specialist	15
Referral for peer support	3
Expert advice through email	37
Info through Facebook	1
Expert advice through Twitter	1
Became regional peer supporter	4

## Web-users' Enquiries:

**UK** 'am getting married in a month... had had oral sex with SW....what is my risk....am going crazy with worry...'

**USA central** 'was found HTLV-1 positive... what does this mean....have two kids....their results are not back yet...feel so guilty....have had only 2 partners in my life....am so scared...'

**USA East coast** '... went to donate blood...now they say they don't want my donation...I may have HTLV...what does this mean....how can I be absolutely sure...'

**USA South** '....parent has HAM/TSP...he wont go to doctors.... do I need a test?'

## Feedback:

The social media has received 100% positive patient feedback.

## Patients' Quotes:

'Thank you so much for helping so much so quickly.'

'Thank you for connecting me with the experts...I have just received my results. I am HTLV negative.'

'Just wanted to let you know and thank you from the bottom of my heart for your help.'

'Have contacted the experts you linked me up with...great team...my viral load is low...now I am less worried...'

'....You are God sent...wished had found you earlier.'

'...I would like to become a patient representative for my region...pl ease add me to your data base...'

**Conclusion:** [www.HTLVaware.com](http://www.HTLVaware.com) has been accessed by web-users for information internationally and has recently been translated into Spanish. It has received 100% positive feedback and provides a platform for information exchange, support and referral to local HTLV specialists. We are grateful to web-users, peer supporters and HTLV experts for their support and guidance.