

To: Dr. E. Jane Carter, President, The Union
Dr. Jose Luis Castro, Director of Publications, The Union
Clare Pierard, Managing Editor, The Union
CC: Stacie C. Stender, Chair, The Union Coordinating Committee of Scientific Activities
Dr. Edward Nardell, TB Section Chair, The Union Coordinating Committee of Scientific Activities
Dr. Kevin Schwartzman, TB Section Program Secretary, The Union Coordinating Committee of Scientific Activities
Wing-Wai Yew, Editor-in-Chief, International Journal of Tuberculosis and Lung Disease
Dr. Martien Borgdorff, Editor-in-Chief, International Journal of Tuberculosis and Lung Disease
Dr. Guy Marks, Editor-in-Chief, International Journal of Tuberculosis and Lung Disease

10 March 2015

Open letter: Retiring stigmatizing and criminalizing language from the global TB discourse

Dear Drs. Carter and Castro,

We congratulate the International Union Against Tuberculosis and Lung Disease (the Union) on record attendance at the 45th Union World Conference on Lung Health in Barcelona and acknowledge ongoing efforts to improve communication, engagement, and inclusion of TB-affected communities in all activities of the organization, especially planning and participation in the 46th Union World Conference on Lung Health in Cape Town this year.

At last year's conference in Barcelona, we were surprised and disappointed to see many abstracts and presentations that included words that we, as a global TB community, have agreed to no longer use because of their stigmatizing connotations. As far back as 2011, the Stop TB Partnership (STBP) published a *Tuberculosis Terminology Guide*,¹ encouraging the retirement of criminalizing and stigmatizing language like 'defaulter,' 'suspect,' and 'TB control' from the global TB discourse. For example, the *Guide* recommends replacing these terms with "person lost to follow-up," "person to be evaluated for TB," and "TB prevention and care," respectively. In 2012, the Union's own *International Journal of Tuberculosis and Lung Disease* published a call to adopt patient-centered terminology in tuberculosis services.² It is important that such terms also become the standard in TB research, given the way that the science of TB shapes clinical practice and care.

We urge the Union to put review mechanisms in place for manuscripts published in the *International Journal of Tuberculosis and Lung Disease* and abstracts accepted for presentation at the annual Union World Conference on Lung Health to ensure that authors use widely agreed upon, appropriate, and sensitive language that respects the dignity of people with TB. Suggested preliminary steps are to include a guidance note on language and a link to the STBP's *Tuberculosis Terminology Guide* when issuing the call for

abstracts for this year's conference and to ask manuscript authors who use stigmatizing language to remove such terminology when they revise and resubmit papers.

Language is very powerful—it is important for all of us to change the way we speak and write about this disease. We hope that this letter and actions taken by the Union will open a dialogue between advocates, members of civil society, researchers, health professionals, and academics necessary to truly eliminate stigmatizing terminology in TB. We welcome continued engagement and collaboration to advance this effort and ask that you please direct future correspondence to mike.frick@treatmentactiongroup.org.

Sincerely,

Community Research Advisors Group (CRAG), Global
Aequitas, India
Community Partners, Global
Global Coalition of TB Activists (GCTA), Global
Global TB Community Advisory Board, Global
International Community of Women Living with HIV–Eastern Africa, Uganda
Kenya AIDS NGOs Consortium (KANCO), Kenya
Moldova Society Against Tuberculosis (SMIT), Moldova
Pereboi.net.ua, Ukraine
RESULTS Australia, Australia
RESULTS Canada, Canada
Stop TB Partnership, Switzerland
TB Europe Coalition, Europe
Treatment Action Group, U.S.A.
U.S. National Society of TB Clinicians, U.S.A.
Wote Youth Development Projects, Kenya

¹ Stop TB Partnership. Suggested language and usage for tuberculosis care, communications and publications. Geneva, Switzerland: Stop TB Partnership, 2011. Available from: <http://www.stoptb.org/assets/documents/about/cb/meetings/22/2.12-13%20Closing/2.12-13.2%20TB%20language%20guide.pdf>.

² Zachariah R, Harries A, Srinath S, et al. Language in tuberculosis services: can we change to patient-centered terminology and stop the paradigm of blaming the patients. *Int J Tuberc Lung Dis.* 16(6):714–17. doi: 10.5588/ijtld.11.0635.