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22 January 2018

Standing Committee on Health
Sixth Floor, 131 Queen Street
House of Commons
Ottawa ON K1A 0A6
Canada
By e-mail: HESA@parl.gc.ca

Honourable Ginette Petitpas Taylor
Minister of Health
By e-mail: hccminister.ministresc@canada.ca

Re: Study of federally funded health research in Canada

With this letter, I would like to draw the Standing Committee's attention to the issue of neglected tropical diseases (NTDs) for consideration during the study on the important matter of federally funded health research with the goal of lowering drug costs and increasing access to medicines both in Canada and globally. With this letter, I would like to recommend increasing Canadian involvement and investment to the control and elimination of NTDs. Specifically,

I propose that the committee increase Canadian commitment to research and development for neglected tropical diseases (NTDs) to join and support the significant global efforts currently underway.

Neglected Tropical Diseases are a collection of 20 communicable diseases that are prevalent in sub-tropical and tropical regions.¹ These diseases affect primarily those individuals who have been included in "the bottom billion"²; i.e. people considered to be the poorest in the world, living on less than \$1.25 USD a day. NTDs coexist in 56 out of the 58 countries considered as home to the bottom billion.³ NTDs perpetuate the cycle of poverty by further disabling sufferers, inhibiting economic development and preventing children born into endemic communities from reaching their potential. It is estimated that NTDs are responsible for 26.06 million Disability-Adjusted Life Years (DALYs) in the last Global Burden of Disease

¹World Health Organization : http://www.who.int/neglected_diseases/diseases/en/

² Collier P. The bottom billion: why the poorest countries are failing and what can be done about it. Oxford: Oxford University Press, 2007: 3–13.

³ Hotez PJ et al. Rescuing the bottom billion through control of neglected tropical diseases. Lancet 2009; 373: 1570–75



study (2010). However, this figure is believed to underestimate the real burden of NTDs due to the long-term nature of infection, presence of chronic manifestations, loss of income, social stigma and burden to the health care system. NTDs have been called by some the “4th leg of the table built by HIV/AIDs, tuberculosis and malaria” due to their contribution to overall global burden of disease.⁴

The global community has responded to the need to control, eliminate and eradicate these diseases of poverty. The London Declaration on Neglected Tropical Diseases consolidates the commitments of donors, pharmaceutical companies, academic research institutions and nongovernmental organisations towards clear goals outlined in a Roadmap for success.⁵ This unprecedented partnership has provided millions of dollars of free NTD treatments for people who would never be able to pay for them. In 2016, one billion people were treated for at least one NTD.⁶ On January 30, 2017 a Guinness World Record was achieved when over 207 million doses were delivered for distribution in a 24-hour period.⁷ Uniting to Combat NTDs has recently published their 5th Report, with an introduction by Dr. Tedros Adhanom Ghebreyesus, the Director-General of the World Health Organization. In this report, the global gains on the Roadmap have been reported as have the current gaps to achieve success.⁸

One of the key priority gaps where research and development is urgently needed is ensuring access to these medicines for all those who need them. NTD drugs are delivered under the direction of the Ministries of Health and Education, depending on the treatment offered (e.g. school based for soil transmitted helminths and schistosomiasis; volunteer community drug distributors for onchocerciasis and lymphatic filariasis). Distribution is conducted under the supervision of the local health service, which can be under resourced and under financed. As such, feasible delivery platforms that create and sustain demand in the community are needed. Creating these delivery platforms is an area of research that has been largely ignored to date. As we advance towards elimination and control, ensuring access to treatment for the most marginalised has become of paramount importance to the global community.^{9,10} Our understanding of the extent to which women and girls are part of the most marginalised remains an issue of great concern.

As one of the researchers working in this area, I have collaborated with national governments (Indonesia, Cote d’Ivoire, Uganda, India, Papua New Guinea and Haiti) and national research institutions to improve access for communities to these free NTD treatments. By conducting social science research, we have understood what approach and kinds of promotional messages to use^{11,12},

⁴ Hotez PJ, Alvarado M, Basa´nez M-G, Bolliger I, Bourne R, et al. (2014) The Global Burden of Disease Study 2010: Interpretation and Implications for the Neglected Tropical Diseases. *PLoS Negl Trop Dis* 8(7): e2865. doi:10.1371/journal.pntd.0002865

⁵ <http://unitingtocombatntds.org/london-declaration-neglected-tropical-diseases/>

⁶ <https://www.voanews.com/a/treatment-painful-tropical-diseases/4163987.html>

⁷ <http://unitingtocombatntds.org/news/guinness-world-record-2017/>

⁸ <http://unitingtocombatntds.org/reports/5th-report/>

⁹ Jacobson J and Bush S (2017) Neglected Tropical Diseases, Neglected Communities, and Conflict: How do we leave no one behind? *Science & Society*. DOI: <http://dx.doi.org/10.1016/j.pt.2017.10.013>

¹⁰ Hotez PJ (2017) Global urbanization and the neglected tropical diseases. *PLoS Negl Trop Dis* 11(2): e0005308.

¹¹ Krentel A et al. (2016) Improving Coverage and Compliance in Mass Drug Administration for the Elimination of LF in Two ‘Endgame’ Districts in Indonesia Using Micronarrative Surveys. *PLoS Negl Trop Dis* 10(11): e0005027.

how to best deliver the pills using volunteers¹³ and how to ensure people overcome the many barriers to uptake.¹⁴ Despite these and other important efforts, there remain urgent calls to expand operational research in this area as the need to provide access to treatment for the most marginalised communities increases.

As a Canadian researcher, I know that Canada can add experience and value to the current global efforts underway to eliminate NTDs. Canada has demonstrated evidence of success in its maternal, newborn and child health agenda. The newly released International Assistance Policy provides a gender equity focus that needs to be adapted in the NTD research community. Unfortunately to date, Canadian commitments to the global NTD efforts have been minimal. Of CIHR funding over a ten-year period, less than 0.5% of total CIHR grants were committed to NTDs.¹⁵ In fact, Canadian funds to global health research and development in general has been low in scale compared to other G7 partners, and can be characterised by both its lack of diversity and inconsistency.¹⁶

As such, I would call on the committee to consider NTDs as a key area for inclusion in the HESA study, particularly with regards to its importance for Canada and Canadians. Specifically,

- Canada is committed to achieving the Sustainable Development Goals; the control, elimination and eradication of NTDs will make a direct impact on goals 1, 3 and 5.¹⁷
- Canada is committed to improving the health of women and children globally. By increasing R&D in NTDs Canada will ensure better health, social and development outcomes for these individuals.
- With the recent feminist International Assistance Policy launched by Canada, Canadian researchers can add value to the current gaps in understanding of how NTDs affect women and girls differently.
- By joining an established global partnership, Canada will ensure that their research and development dollars would be used for greater impact.
- Canadian researchers already actively involved in NTD research and development would gain value from increased government visibility and support both in policy as well as in financial terms.
- Canadian research institutions and researchers have longstanding relationships with academic institutions in low and middle income countries that would benefit from increased Canadian investment.

¹² Krentel A et al. (2006) Using knowledge, attitudes and practice (KAP) surveys on lymphatic filariasis to prepare a health promotion campaign for mass drug administration in Alor District, Indonesia. [Trop Med Int Health](#). 2006 Nov;11(11):1731-40.

¹³ Krentel A et al. (2017) Review of the factors influencing the motivation of community drug distributors towards the control and elimination of neglected tropical diseases (NTDs). *PLoS Negl Trop Dis* 11(12): e0006065.

¹⁴ Krentel A et al. (2013) A Review of Factors That Influence Individual Compliance with Mass Drug Administration for Elimination of Lymphatic Filariasis. *PLoS Negl Trop Dis* 7(11): e2447.

¹⁵ Goulding R and Nickerson JW (2010) Fostering Canadian drug research and development for neglected tropical diseases. *Open Medicine* 4(2):E117.

¹⁶ Garnham S and Baodu NY (2017) "Mapping Canadian R&D for Diseases of Poverty." Global Poverty Solutions Report. http://globalpovertysolutions.ca/_docs/GPS%20Neglected%20Diseases%20R&D%20Report%20FINAL%20English.pdf

¹⁷ UN. (n.d.). Sustainable development goals 17 goals to transform our world. Retrieved January 15, 2018 from <http://www.un.org/sustainabledevelopment/sustainable-development-goals/>

- Canadian students would benefit from increased opportunities to become trained and involved in global health research, creating leaders for the next generation.

With the Canadian presidency of the G7 this year, Canada is poised to demonstrate to the world its leadership and commitment to improving the lives of the poorest and most vulnerable populations. Three of the G7 themes directly intersect with the efforts to control and eliminate NTDs: gender equality and women's empowerment, building a more peaceful world and investing in growth for everyone. Canada has an opportunity to convey its commitment to these values through the Standing Health Committee's recommendations to include NTDs in their remit.

I look forward to the Standing Health Committee's deliberations. I urge the Committee to consider NTDs as a platform for Canadian involvement and investment during the study of federally funded health research. Stopping the cycle of poverty for the most vulnerable populations contributes to a better and more equitable world for everyone.

Please do not hesitate to contact me if any assistance is required in this important work.

Respectfully yours,



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