

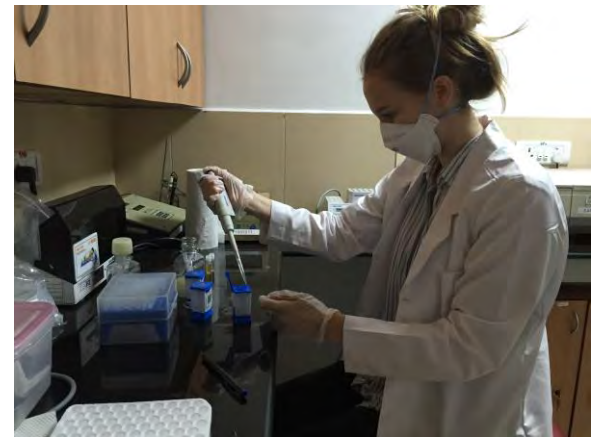
# HOW TO ORGANIZE

# ADVOCACY CAMPAIGNS

ERICA LESSEM  
MADLEN NASH  
FEBRUARY 2024

Photo: David Harrison for Treatment Action Campaign  
Thanks to Mike Frick, Lizzy Lovinger, and Suraj Madoori at TAG

# ABOUT US



# WHAT IS POLICY?

A **policy** is a deliberate system of principles to guide decisions and achieve rational outcomes. A **policy** is a statement of intent, and is implemented as a procedure or protocol

Types: federal/fiscal, global, regulatory, corporate, etc.

Examples:

- Guidelines for the treatment of MDR-TB
- Federal or provincial funding commitments
- Rules protecting the rights of people with TB (or any person) involved in research
- A 17% funding allocation for TB in Global Fund
- A pharmaceutical company's drug pricing policy

# HOW DOES POLICY EFFECT YOU?

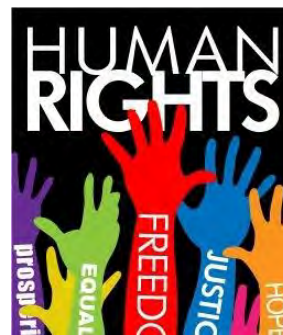
- **Govern the way YOU operate within a system**
- **Govern the way an individual accesses a system**
- **Create or limit access**
- **Increase or decrease exposure to harms**
- **Determine what gets resources and what doesn't**

# UNPACKING ADVOCACY: FROM GRASSROOTS TO GRASSTOPS

# WHAT IS ADVOCACY?

10 advocates = 10 definitions of advocacy

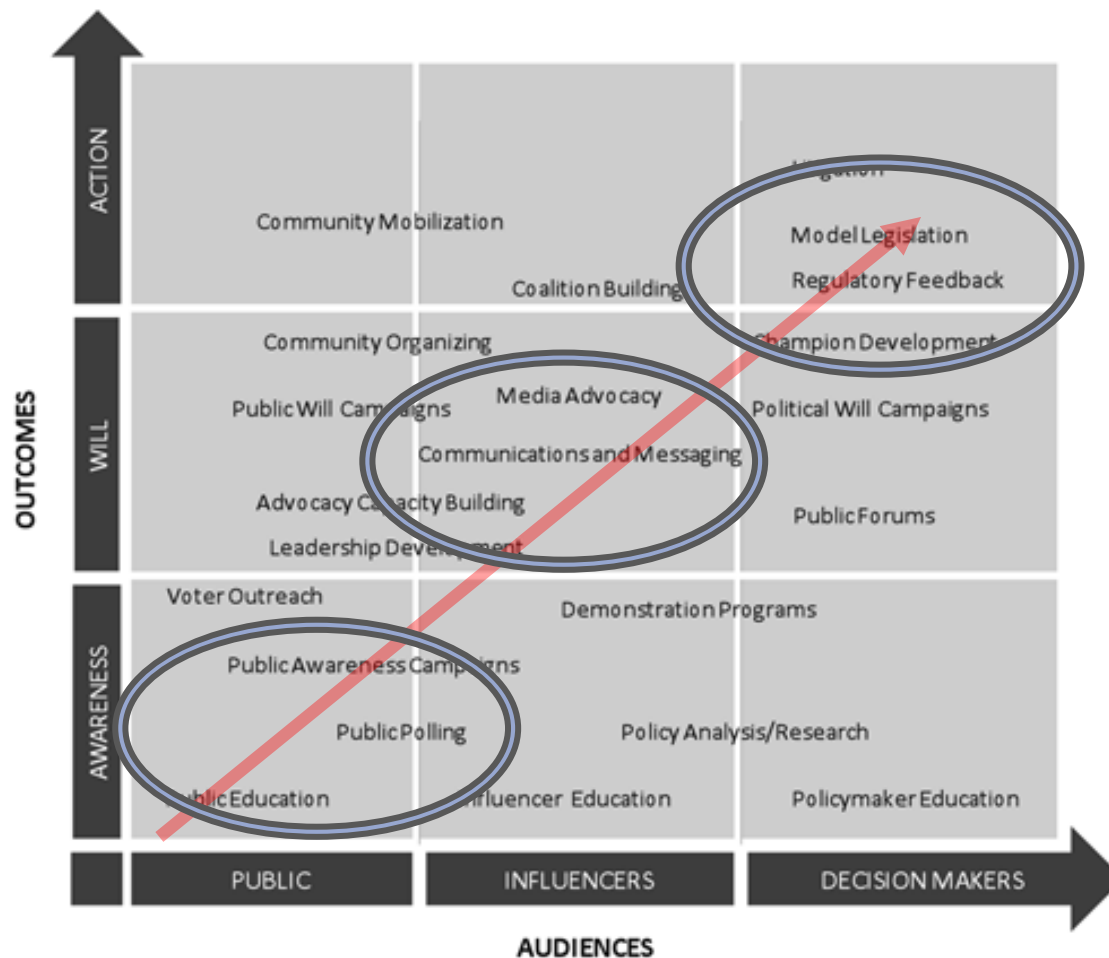
“Advocacy is a set of **tactics** aimed at influencing **decision-makers** and people in power to make **systemic changes** to laws, policies and practices. Some advocacy tactics include pursuing litigation, appealing to higher standards such as ethics or international law, harnessing the power of the media and mobilizing communities.”



*Know it, Prove it, Change it: a Rights Curriculum for Grassroots Groups*

# ADVOCACY: NO SECRET SAUCE

Visual Framework of Public Policy Strategies



WHY DO WE NEED ADVOCACY FOR  
TB?

**14,600 PILLS. DAILY PAINFUL INJECTION.  
VOMITING. DIARRHOEA. HALLUCINATIONS  
SUICIDAL FEELINGS. DEAFNESS.**

**THIS IS NOT GOOD ENOUGH.**

**#COUGHUPTHE TB MONEY**

# ELEMENTS OF A SUCCESSFUL POLICY ADVOCACY CAMPAIGN

- Evidence
- Coalition
- Targets
- Clear ask
- Framing
- Tactics

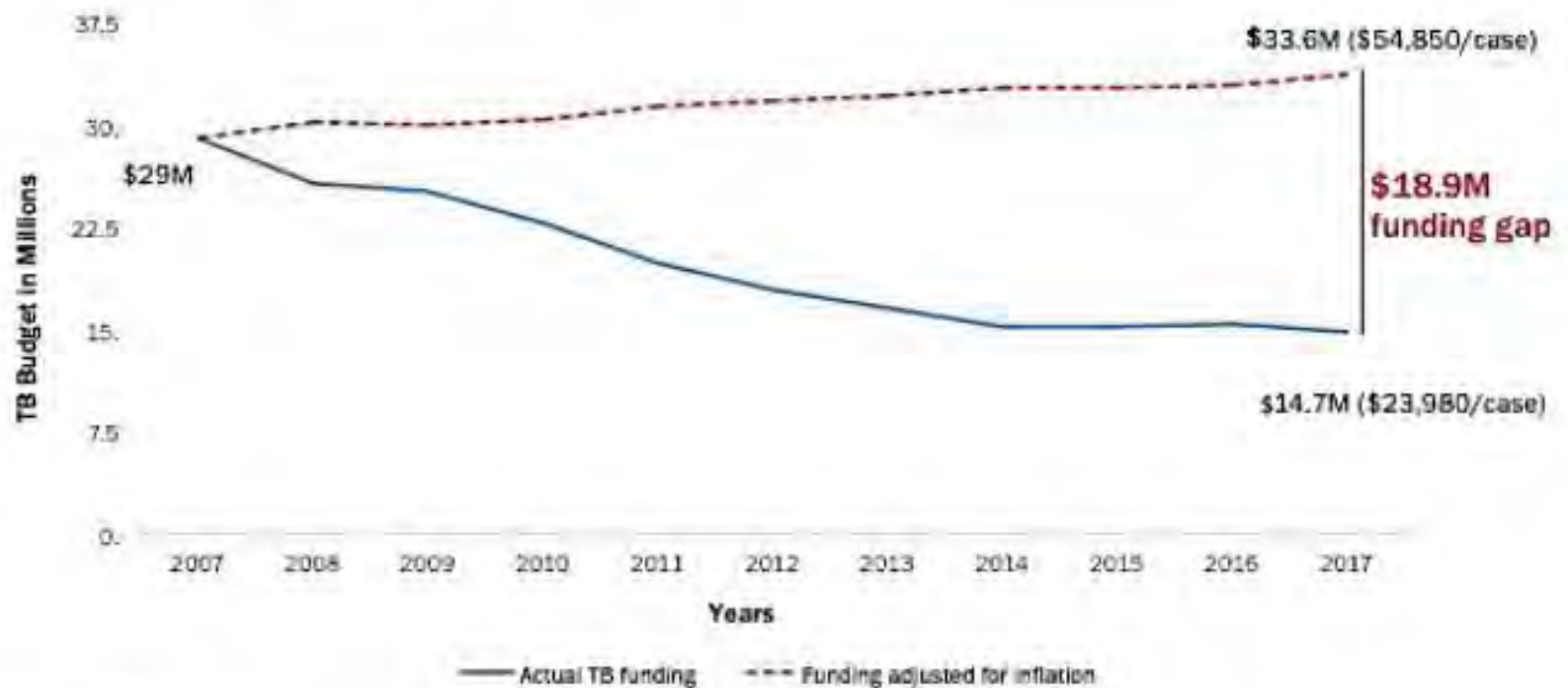
...and a lot of hard work...

*PS connections and relationships help*

EXAMPLE CAMPAIGN 1:  
COMBATING RISING TB IN  
NYC

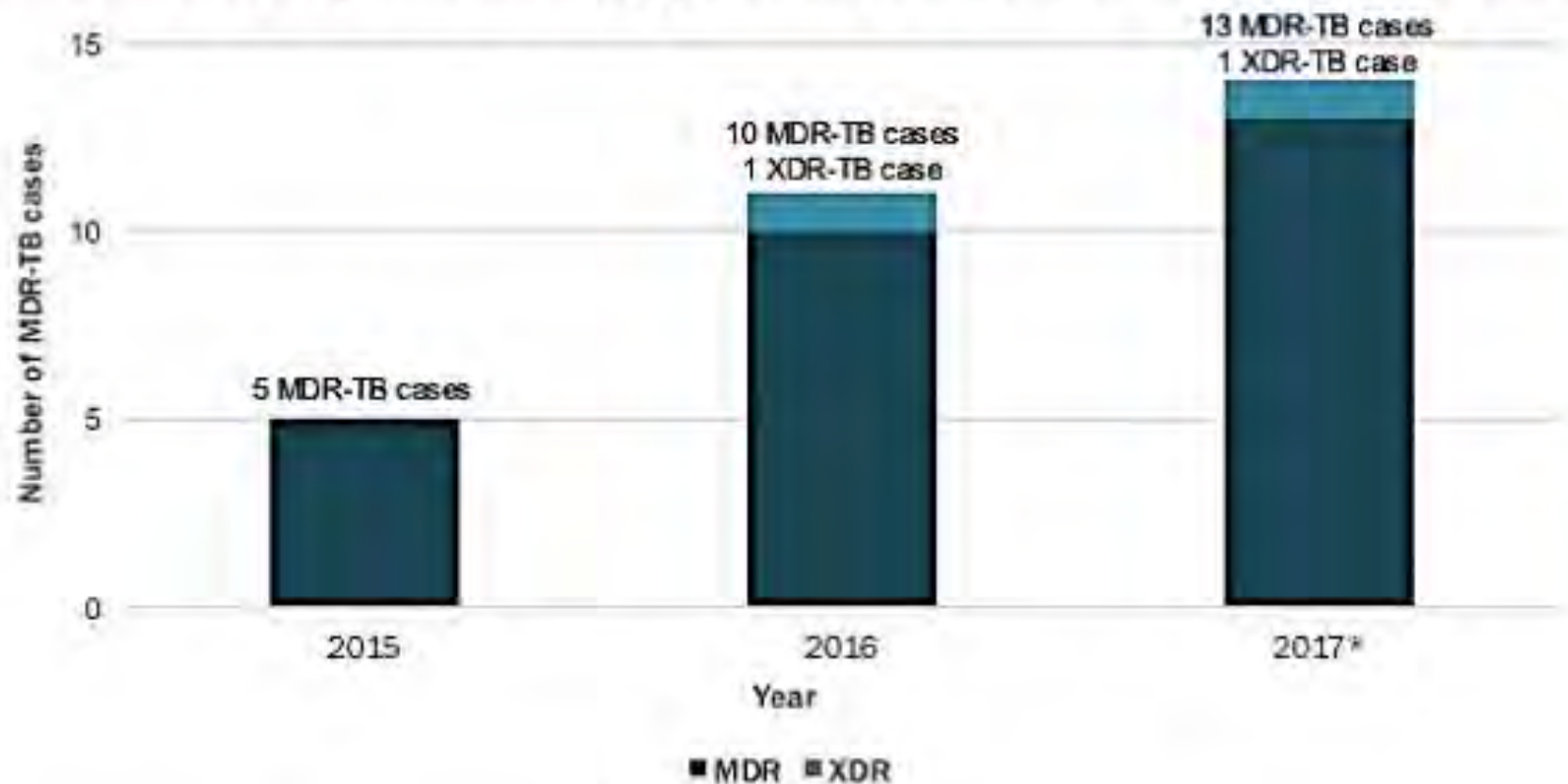
# EVIDENCE

## New York City Department of Health and Mental Hygiene TB Funding and Funding Adjusted for Inflation, 2007-2017



# EVIDENCE

## Since 2015, Multidrug-Resistant TB is on the Rise



# EVIDENCE

## **List of Chest Centers**

Full-time (*losing Saturday hours*):

- Fort Green
- Corona

Part-time:

- Morrisania
- Washington Heights

Closed:

- Brownsville
- Bushwick
- Jamaica
- Bedford
- Chelsea
- Richmond

# WHO COUNTS AS A PARTNER?

“Comrades, the lack of investment in TB is a political problem. It is political, because at its essence it is about governments not being held accountable for failing to respond to TB. **We can’t win this battle if we don’t make it a political battle. And to make it work as a political battle, we will have to put poor people from affected communities at the center of the response.** We will have to organize and mobilize. We must fight this battle in the boardrooms. We must take it to the streets. And, if we have to, we must take it to the courts.”

— Anele Yawa, General Secretary, Treatment Action Campaign, closing speech to 2015 Union World Conference on Lung Health

# COALITION

**Academy of Medical & Public Health Services**

**African Services Committee**

**Apicha Community Health Center**

**Boom! Health**

**Callen-Lorde Community Health Center**

**NY Care for the Homeless**

**New York End AIDS Now**

**NY Exponents Inc.**

**New York Federation of Protestant Welfare Agencies,**

**GMHC**

**Hispanic Federation**

**Housing Works**

**Latino Commission on AIDS**

**New York Legal Action Center**

**Mexican Coalition**

**National TB Controllers Association**

**New York-Presbyterian Lower Manhattan Hospital,**

**The New York Immigration Coalition**

**Treatment Action Group**

**Unity Fellowship of Christ Church**

# IT WORKS THE OTHER WAY, TOO

**Researchers and clinicians can be great, powerful advocates.**

**Students can bring new ideas and energy to make TB an issue we can claim and conquer.**

# TARGETS\*

**NYS legislature**

**Mayor's Office**

**City Council\***

*\*Targets become allies*

**To:** Mayor Bill de Blasio, New York City  
Speaker Corey Johnson, New York City Council  
Council Member Alicka Ampry-Samuel  
Council Member Inez Barron, Member of the Committee on Health  
Council Member Margaret Chin, co-Vice Chair of the Black, Latino/a, and Asian Caucus  
Council Member Robert E. Cornegy Jr.  
Council Member Laurie Cumbo  
Council Member Daniel Dromm  
Council Member Rafael L. Espinal Jr.  
Council Member Mathieu Eugene, Member of the Committee on Health  
Council Member Vanessa Gibson  
Council Member Rory I. Lancman  
Council Member Mark Levine, Chair of the Committee on Health  
Council Member Carlos Menchaca, Chair of the Committee on Immigration  
Council Member Francisco Moya  
Council Member Keith Powers, Member of the Committee on Health  
Council Member Carlina Rivera, Chair of Committee on Hospitals  
Council Member Ydanis Rodriguez  
Council Member Deborah Rose  
Comptroller Scott Stringer  
Bronx Borough President Ruben Diaz  
Brooklyn Borough President Eric Adams  
Manhattan Borough President Gale Brewer  
Queens Borough President Melinda Katz  
Public Advocate Letitia James

**CC:** Deputy Mayor for Health and Human Services Herminia Palacio  
Commissioner Nisha Agarwal, Mayor's Office of Immigrant Affairs  
Louis Cholden-Brown, Deputy Chief of Staff for Legislation, Planning & Budget, New York City Council

March 19, 2018

**Open letter re: Urgent need to restore and increase funding for New York's TB response**

# CLEAR ASK

A restoration of funding to the DOHMH Bureau of TB Control to \$14.89 million (a \$6.3 million increase over the current year)

# FRAMING

- Data-driven
- Don't repeat history – M/XDR outbreak of 90s
- Acting now saves money
- Center vulnerable populations

# TACTICS

Policy brief

Meetings with officials

Constituent contacts to elected representatives

Finding champions

Open letters

Public action – City Hall demo

Testimony at City Council budget hearings

Media coverage



RESULT: 20% INCREASE  
TO NYC BUDGET

RESULT: 20% INCREASE TO  
NYC TB BUDGET\*

\* ***FOR THAT YEAR...***

EXAMPLE CAMPAIGN 2:  
ACCESS TO CHILD-  
FRIENDLY TB  
FORMULATIONS IN CANADA



# PEDS FORMULATIONS IN CANADA AWARENESS



"We tried it all to get small kids to take the pills: applesauce, yogurt, anything with some liquid. Kids find it much harder than adults to take the drugs, it's a huge amount of pills. Kids also get scared to see the red pill that's crushed. INH [one of the anti-TB drugs] tastes worse so we give it first. We have to use tricks to get children to take it."

— Inuk TB DOT Worker

# PEDS FORMULATIONS IN CANADA

## EVIDENCE



### Prequalification of Medical Products

IVDs, Medicines, Vaccines and Immunization  
Devices, Vector Control

61% of ALL  
childhood TB in  
Canada occurs  
among Indigenous  
kids

### WHO Model List of Essential Medicines for Children - 9th list, 2023

26 July 2023 | Technical document

- More than **one million treatment courses** have been ordered.
- **123 countries and counting** have adopted the improved medicines. These countries account for more than 75% of the global pediatric TB burden.

INH is 10-15 mg/kg/day (maximum 300 mg).<sup>23</sup> Administration is affected by food and INH is better absorbed on an empty stomach. Fat and sugars reduce its absorption.<sup>61</sup> A sorbitol-

# PEDS FORMULATIONS IN CANADA

## STAKEHOLDER OUTREACH = FAR & WIDE

- Affected communities, patients, families, local leadership
- Indigenous organizations – NTI, ITK, QRH
- Government agencies — PHAC, Indigenous Services, Health Canada, Government of Nunavut, FNIHB, NML
- Non-profits — Global Drug Facility, Partners in Health
- Industry — Pharmaceutical companies
- Healthcare providers — Nurses, frontline community workers, physicians/academics → Canada and beyond

# PEDS FORMULATIONS IN CANADA

## FRAMING = DOUBLE STANDARD

### Project profile – Global Drug Facility: Provision of Anti-Tuberculosis Drugs

Search for proje

Overview €

Project number

Maximum contribution

#### Results achieved ⓘ

Results achieved by Global Drug Facility, through the support of the Government of Canada and other international donors, as of March 2016 include: (1) provided quality-assured treatments since 2001 for more than 27 million patients with tuberculosis (TB), This included over 184,000 patient treatments for multi-drug resistant TB (MDR-TB) and 1.5 million treatments for children; (2) delivered over 1.5 million patient treatments, including over 219,000 pediatric treatments in 2015; (3) provided capacity-building support to 134 countries since 2001, including training and workshops, monitoring missions and technical assistance to improve the management of drug supplies; (4) contributed to planning and guidance for the global introduction of new child-friendly medicines for pediatric TB; and (5) provided a mechanism for countries to order the new pediatric formulations and made grants available to eligible countries to purchase pediatric TB medicines with funding from Global Affairs Canada.

\$37,121,095



UNITED NATIONS  
HIGH-LEVEL MEETING ON THE  
FIGHT AGAINST TUBERCULOSIS  
26 SEPTEMBER 2018, UNHQ, NEW YORK

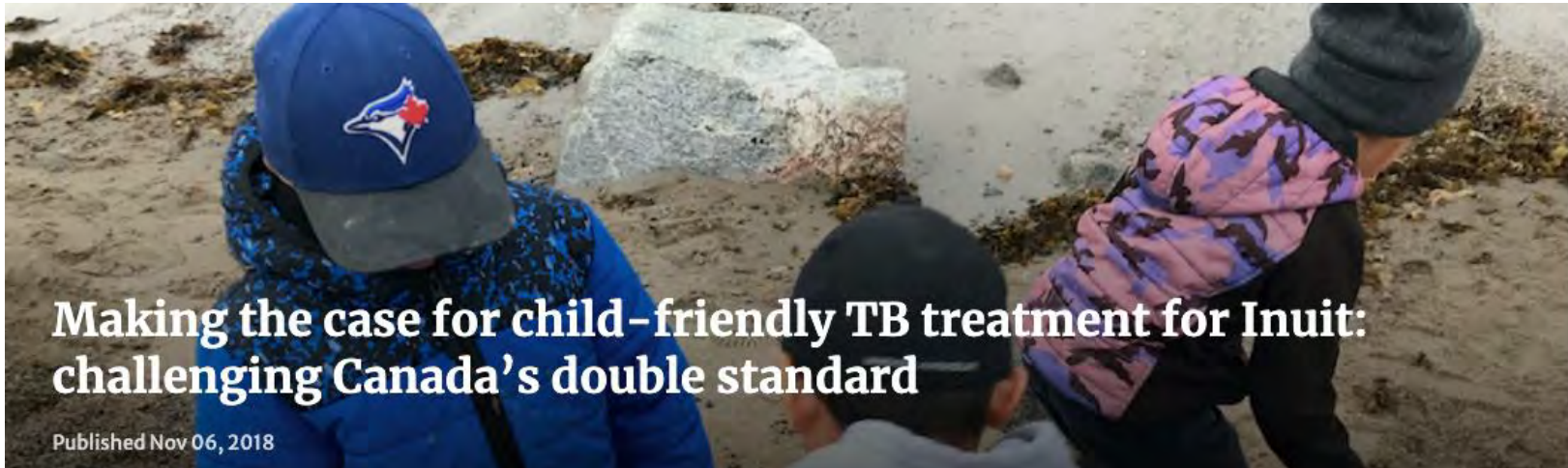
By signing on to the United Nations political declaration on TB, Canada has committed “to promote equitable access to child-friendly formulations of medicines to optimize the prevention and treatment of drug-sensitive and drug-resistant tuberculosis among children”.

# PEDS FORMULATIONS IN CANADA

## TARGETS = MANY

- Provincial and federal → always have to think about jurisdiction in Canada!
- Practicing physicians

# PEDS FORMULATIONS IN CANADA TACTICS



## Making the case for child-friendly TB treatment for Inuit: challenging Canada's double standard

Published Nov 06, 2018



**Madlen Nash**  
MSc Student, M



LANCET  
& Adolescent Health

Submit Article



CBC  
@CBC

I just sent an email with more details -- to madlen.nash at mail dot mcgill etc -- We saw your recent article in Nature and would love to chat with you about children and TB. Is this something you have time to talk about today? My phone number is 867-444-8025

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COMMENT | VOLUME 4, ISSUE 12, P855-857, DECEMBER 2020

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Finding allies!



Subscribe

## Access to paediatric formulations for the treatment of childhood tuberculosis

Madlen Nash • Christophe Perrin • James A Seddon • Jennifer Furin • Janika Hauser • Ben Marais • et al.

Show all authors

Published: December, 2020 • DOI: [https://doi.org/10.1016/S2352-4642\(20\)30273-X](https://doi.org/10.1016/S2352-4642(20)30273-X)

Check for updates

# PEDS FORMULATIONS IN CANADA

## MULTIPLE VOICES



ᐃᓄᐃᑦ ᑕᐱᓃᑦ ᑲᓇᑕᑦ  
INUIT TAPIRIIT KANATAMI

## Inuit Tuberculosis Elimination Framework

1.6 Equitable access to new TB/LTBI drugs/treatment options across Inuit Nunangat such as 3HP and fixed-dose combinations for the treatment of TB in children, supported with adequate infrastructure and standardized protocols for use

### ᐃ Time for Canada to align with global innovations in treatment for tuberculosis

Adam R. Houston and Elizabeth Rea

CMAJ July 31, 2023 195 (29) E985-E986; DOI: <https://doi.org/10.1503/cmaj.230246>

Article

Responses

Metrics

PDF

#### KEY POINTS

- Novel regimens for treating tuberculosis offer faster, safer, more effective treatment.
- Key drugs underpinning these novel regimens, some of them decades old, are not marketed in Canada.
- Tools are available that could improve access in Canada, including recent Canadian regulatory changes and existing international mechanisms like the Global Drug Facility.

#### In This Issue



CMAJ

Vol. 195, Issue  
31 Jul 2023

Table of Contents  
Index by author

# PEDS FORMULATIONS IN CANADA

## RESULTS = NONE YET...

**ALERT**

### **New Canadian Tuberculosis Standards 8<sup>th</sup> Edition**

**Tuesday May 17, 2022**

Table 4). Given the difficulties with taste (ethambutol is particularly unpalatable) and ability to swallow pills, administration of these medications to very young children may require multiple tries of different formulations (eg, crushed pills in different foods, suspensions, etc). More research is needed in this area for children, including the pharmacokinetics of newer TB drugs, the impact of mixing them with food and the stability of suspensions.<sup>60</sup>

---

EXAMPLE CAMPAIGN 3:  
ACTIVISM DELIVERS  
RECENT UNPRECEDENTED  
ACCESS WINS

# ACTIVISM DELIVERS UNPRECEDENTED ACCESS WINS



Aug 30: **55%** price drop for bedaquiline



Sept 19: **20%** price drop for Xpert TB/RR-TB tests



Sept 21: **30%** price drop for 3HP



Sept 30: J&J commits **drop DR-TB patents** on bedaquiline

# CAMPAIGN BEHIND RECENT WINS: TIME FOR \$5



✓ Aug 30: **55%** price drop for bedaquiline

📉 Sept 19: **20%** price drop for Xpert TB / RR-TB tests

💸 Sept 21: **30%** price drop for 3HP

🤝 Sept 30: J&J commits **drop DR-TB patents** on bedaquiline

# TIME FOR \$5 EVIDENCE

“The public sector has invested over \$250 million in the development of both the underlying technologies and the GeneXpert diagnostic platform and assays, and has made additional investments in rolling out the technology in countries with high burdens of TB.”

Table 1

Overview of public contributions to GeneXpert development.

Year	Project name	Funder(s)	Amount (USD) <sup>A</sup>
1992 <sup>B</sup> – 1998	Development of underlying technologies at Lawrence Livermore National Laboratory before creation of Cepheid	U.S. Department of Energy, U.S. Department of Defense (DARPA, U.S. Army)	≥10,674,919 <sup>B</sup>
1998– 2006	SBIR/STTR funding	Department of Health and Human Services, U.S. Department of Defense (U.S. Army)	9,601,010
2002– 2018	NIH grants for research relating to pre-market technology development	U.S. Department of Health and Human Services (NIH)	42,077,663
2011– 2020	NIH grants for validation research (testing real-world effectiveness)	U.S. Department of Health and Human Services (NIH)	13,732,770
1996– 2020	R&D tax credits (see <a href="#">S2 File</a> )	U.S. federal and state governments	66,815,060
2001 <sup>C</sup>	Micro-fluidic Integrated DNA Analysis System (MIDAS)	U.S. Department of Defense (Edgewood Research, Development and Engineering	3,455,708

# TIME FOR \$5 EVIDENCE

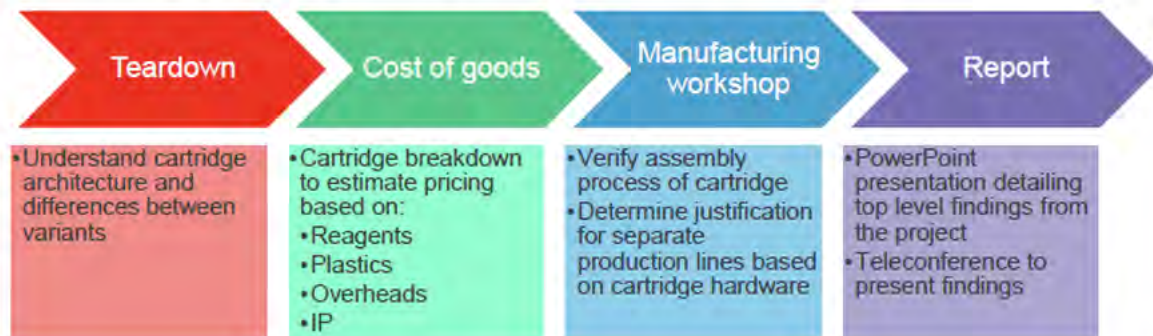
## Cost of goods (COGS) of the Xpert cartridges

### What

Cost of goods sold (COGS) = the direct costs of producing the goods sold by a company

- includes the cost of the materials and labor directly used to create the good
- excludes indirect expenses e.g. distribution costs

### How



2012: Xpert MTB/RIF  
2015: Xpert HIV  
2018: Xpert MTB/RIF ultra  
Xpert HCV

# TIME FOR \$5 COALITION



125+ civil society organizations

TIME FOR \$5  
TARGET

Cepheid → Danaher

TIME FOR \$5

CLEAR ASK

*pop quiz*

TIME FOR \$5

CLEAR ASK

***Devil is in the details:***

-inclusive of service & maintenance

-\$5 for ALL test cartridges

# TIME FOR \$5 FRAMING



“printer ink model”

“It's pure price gouging. It's pure profiteering.”- *Stijn Deborggraeve, MSF Access Campaign*

# TIME FOR \$5 TACTICS

- **21 October 2019:** The first “Time for \$5” open letter called on Cepheid to reduce the price of TB cartridges to \$5, inclusive of service and maintenance (127 civil society signatories).
- **31 October 2019:** Civil society protesters interrupted a session on Xpert at the Union Conference, presented the “Time for \$5” demands to Cepheid, and distributed 500 copies of the first open letter to participants at the conference.
- **4 November 2019:** Cepheid responded to the first open letter, did not deny the manufacturing efficiencies, but said these efficiencies supported investments in tests for other diseases.
- **6 January 2020:** The second “Time for \$5” open letter expanded the \$5 ask to include other Xpert tests for HIV, hepatitis B & C, HPV, and STIs (156 civil society signatories).
- **27 March 2020:** TAG and MSF released statements calling on Cepheid to lower the price of its SARS-CoV-2 test for COVID-19 to \$5, and against the company’s profiteering from the pandemic.
  - <https://msfaccess.org/msf-calls-no-patents-or-profiteering-covid-19-drugs-tests-and-vaccines-pandemic>
  - <https://www.treatmentactiongroup.org/statement/treatment-action-group-statement-on-the-high-price-of-cepheids-xpert-test-for-covid-19/>



# TIME FOR \$5 TACTICS

...*FAST FORWARD*

PHARMALOT STAT+

## Novelist John Green launches attack on Cepheid over the price of its TB test

By [Lizzy Lawrence](#) and [Ed Silverman](#) Sept. 14, 2023 Reprints



UN General Assembly High-level Meeting on the fight against tuberculosis, 2023




# TIME FOR \$5 SUCCESS

## ***UPDATE, 19 September 2023:***

Thanks to your campaigning support, Danaher and Cepheid **announced** they will reduce the price of the main drug-resistant TB test (Xpert MTB/RIF) by 20% in high-TB-burden countries, from \$9.98 to \$7.97 per test. Although not the 50% reduction to \$5 we have been calling for, this price drop is a significant step in the right direction, considering the corporations have refused to reduce the price of this critical test for over 10 years.

# TIME FOR \$5 SUCCESS (PARTIAL)

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Health · [CBC Explains](#)

## 'Pure price-gouging': Advocates celebrate price drop of critical TB test but say Big Pharma needs to do more

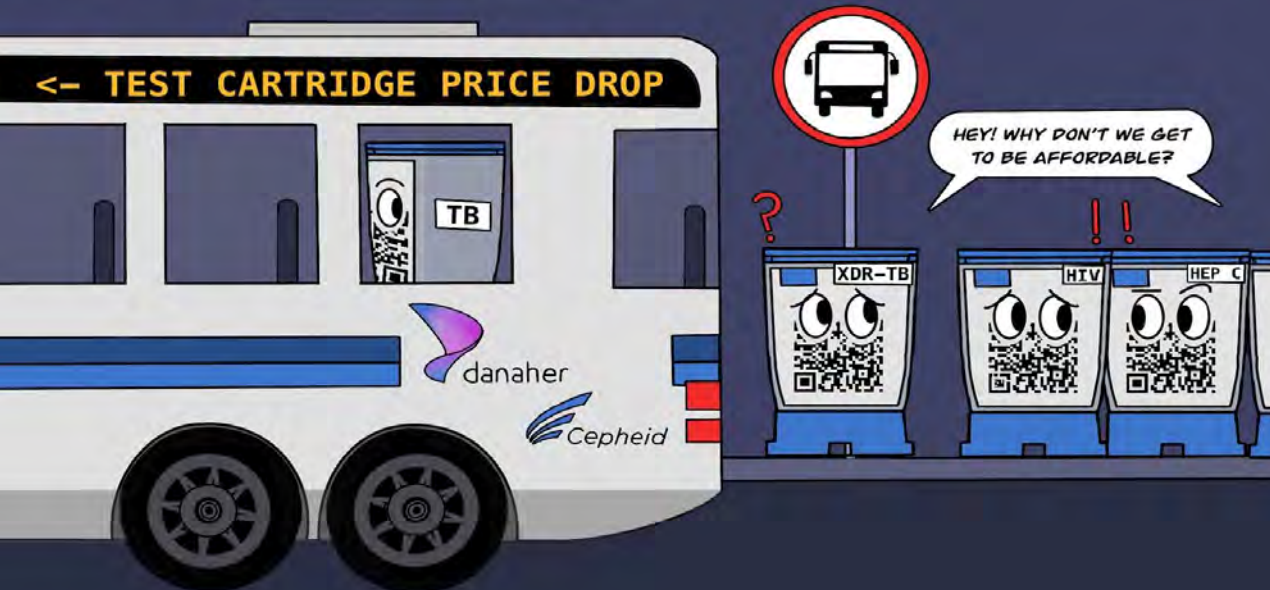
Campaigners denounce conglomerate's 'printer ink' model for critical TB tests



[Darius Mahdavi](#) · CBC · Posted: Sep 19, 2023 12:37 PM EDT | Last Updated: September 19, 2023

# TIME FOR \$5 SUCCESS (PARTIAL)

IT'S TIME FOR \$5!  
XDR-TB TEST NEXT!



A price drop to \$7.97 for only the Xpert MTB/RIF test is not enough.

We need **Danaher & Cepheid** to also drop the price of the Xpert MTB/**XDR** test which is still priced at \$14.90!



# EXERCISE

**You will....**

**Break into groups of 5**

**Choose one of the 3 campaign areas (next slides)**

**Map out your campaign including:**

- Target
- Coalition
- Clear Ask
- Framing
- Tactics

# EXERCISE

## CAMPAIGN A

### **Goal: Canada re-funds TB REACH**

#### **Background**

- TB REACH is an initiative under the Stop TB Partnership, a Geneva-based multilateral institution
- TB REACH aims to “reach more people with TB and revolutionize TB diagnosis and care”
- Canada is the foundational and leading donor to TB REACH
- Since TB REACH began in 2010, 40M+ people screened and 2.6M people diagnosed and put on treatment
- Canada announced CAD25.5M of renewed funding in 2023

# EXERCISE

## CAMPAIGN B

**Goal: Global + country-level reporting for maternal TB indicators**

### **Background**

- Pregnant / postpartum people and their newborns are at increased risk for TB and poor TB outcomes / pregnancy outcomes
- Major gaps in diagnosing and treating TB in pregnancy/postpartum in part due to lack of quantification of problem and accountability
- World Health Organization collects and presents data from countries on a variety of key TB indicators each year in its *Global TB Report*
- Note: reluctance to add more indicators due to onerous requests to countries



# 1/4/6x24 CAMPAIGN



# EXERCISE CAMPAIGN C

## BACKGROUND

### *A FEW WORDS ON ACCESS*



# EXERCISE

## CAMPAIGN C

- Price is about as low as current market will bear thanks to recent price reduction
- Patents prevent generic competition (one of best ways to lower price)
- Following 1/4/6x24 campaign demands, Johnson & Johnson committed to non-enforcement of primary patent for drug-resistant TB disease
  - Generics waiting at the wings are now on the market
- However, secondary patents exist for treating TB infection
  - Note: “patent thicket”, “evergreening”
- SMART4TB has announced plans to test bedaquiline for TB infection
  - Potentially could expand market for bedaquiline from about 500K courses / year to millions

# FINDING YOUR ADVOCACY STYLE

## *FIERCE*



# FINDING YOUR ADVOCACY STYLE *FUNNY*



# FINDING YOUR ADVOCACY STYLE

## *DIPLOMATIC*



# FINDING YOUR ADVOCACY STYLE

*PROVOCATIVE*  
*ARTISTIC*



Gran Fury, 1989

# FINDING YOUR ADVOCACY STYLE ACADEMIC

PLOS ONE

RESEARCH ARTICLE

## Public investments in the development of GeneXpert molecular diagnostic technology

Dzintars Gotham<sup>1\*</sup>, Lindsay McKenna<sup>2</sup>, Stijn Deborggraeve<sup>3</sup>, Suraj Madoori<sup>2</sup>, David Branigan<sup>2</sup>

**1** Independent Researcher, United Kingdom, **2** Treatment Action Group, New York, NY, United States of America, **3** Médecins Sans Frontières-Access Campaign, Geneva, Switzerland

\* [dzintarsgotham@gmail.com](mailto:dzintarsgotham@gmail.com)



### Abstract

#### Background

The GeneXpert diagnostic platform from the US based company Cepheid is an automated molecular diagnostic device that performs sample preparation and pathogen detection within a single cartridge-based assay. GeneXpert devices can enable diagnosis at the district level without the need for fully equipped clinical laboratories, are simple to use, and offer rapid results. Due to these characteristics, the platform is now widely used in low- and middle-income countries for diagnosis of diseases such as TB and HIV. Assays for SARS-CoV-2 are also being rolled out. We aimed to quantify public sector investments in the development of the GeneXpert platform and Cepheid's suite of cartridge-based assays.

#### Methods

Public funding data were collected from the proprietor company's financial filings, grant

#### OPEN ACCESS

**Citation:** Gotham D, McKenna L, Deborggraeve S, Madoori S, Branigan D (2021) Public investments in the development of GeneXpert molecular diagnostic technology. *PLoS ONE* 16(8): e0256883. <https://doi.org/10.1371/journal.pone.0256883>

**Editor:** Susan Horton, University of Waterloo, CANADA

# EXERCISE

## **Goal A**

Canada re-funds TB REACH

## **Goal B**

Global + country-level reporting for maternal TB indicators

## **Goal C**

Affordable bedaquiline for TB prevention

## **Map out your campaign including:**

- Target
- Coalition
- Clear Ask
- Framing
- Tactics

# SMALL GROUP PRESENTATIONS

# THE ROLE OF UNIVERSITIES



**STILL**  
**MEDICINES SHOULDN'T  
BE A LUXURY**



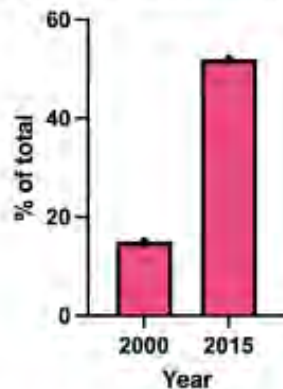
# HARNESS YOUR POWER!



JUSTICE  
IS GLOBAL

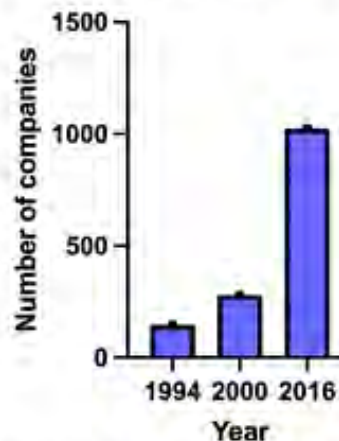
Academic workers are increasingly essential to the production process in globally important industries

Percentage of the 30 top-selling drugs derived from academic institution IP



Huang et al. *Nature Biotechnology* 2021

New biotech startups spun out with university IP



Association of University Technology  
Managers 2016



JUSTICE  
IS GLOBAL



# THANK YOU!

**Questions?**

[ellesem1@jh.edu](mailto:ellesem1@jh.edu)

[mnash12@jh.edu](mailto:mnash12@jh.edu)