



# THE HUMAN SPIRIT

A TB ADVOCACY PROJECT BY THE GDI AND VISUAL EPIDEMIOLOGY



# PRESENTATION OVERVIEW

- PROJECT MISSION AND SUMMARY
- BACKGROUND AND APPROACH
- KEY MESSAGES
- OUTREACH AND ENGAGEMENT
- MONITORING AND EVALUATION
- FUTURE PROJECTS

# WHAT IS THE HUMAN SPIRIT PROJECT?

- THE HUMAN SPIRIT PROJECT AIMS TO PROMOTE A WORLD WITH ZERO DEATHS, ZERO DISEASE, AND ZERO SUFFERING DUE TO TUBERCULOSIS AND DRUG-RESISTANT TUBERCULOSIS.
  - PROMOTE REDUCING THESE BURDENS OF DISEASE IN THE *PATIENT, FAMILY, AND COMMUNITY*
- IT ACCOMPLISHES THIS BY PROMOTING MESSAGING THROUGH THE USE OF:
  - ENGAGING ONLINE SHORT FILMS
  - A COMPREHENSIVE AND INFORMATIVE WEBSITE
  - SOCIAL MEDIA AND SCREENINGS

# THE IDEA BEHIND THE HUMAN SPIRIT

- THE TB EPIDEMIC WILL NOT BE OVERCOME IN ONE GRAND GESTURE, RATHER BY SUSTAINING THE CONTINUED EFFORTS OF THOSE LIVING WITH OR WORKING IN TB
- THE COLLECTION OF FILMS WILL SHOW THIS BY ALLOWING VIEWERS TO SEE THAT THE TB EPIDEMIC IS NOT ONE GIANT EPIDEMIC, BUT A COLLECTION OF INDIVIDUAL BATTLES FOUGHT EVERY DAY

# PURPOSE OF PROJECT COMPONENTS

- SHORT FILMS
  - A GROWING COLLECTION OF FILMS PROFILING PEOPLE LIVING WITH OR WORKING IN THE FIELD OF TB
  - FILMS WILL SHOW VARIOUS SITUATIONS, FROM PATIENTS TO DECISION MAKERS
- WEBSITE
  - WEBSITE WILL HOUSE THE PROJECT AND GIVE A CENTRAL PLACE FOR REFERRALS

# KEY MESSAGES: PREVENTION

- SUPPORT PROGRAMS THAT INCORPORATE THE IMPORTANCE OF SOCIO-ECONOMIC FACTORS INTO PREVENTION METHODS
- RAISE AWARENESS THAT ANYONE CAN GET TB, AND THAT THE DISEASE DOES NOT RESPECT BORDERS OR WEALTH
- ENCOURAGE POLICIES THAT DO NOT RELY ON PASSIVE SURVEILLANCE, BUT INITIATE ACTIVE CASE FINDING AS A MEANS OF PREVENTION
- PUSH THE NEED FOR INNOVATION IN VACCINE RESEARCH
- ADVOCATE FOR CONTINUED RESEARCH TO IDENTIFY CULTURALLY SPECIFIC METHODS OF EDUCATION AND AWARENESS THAT ARE ALSO AIMED AT BREAKING DOWN AND ELIMINATING STIGMA

# KEY MESSAGES: TREATMENT

- PATIENT CENTERED CARE
- DECENTRALIZED PROGRAMS THAT AGGRESSIVELY FIND ACTIVE CASES AND GET PATIENTS ON TREATMENT
- RESEARCH FOR BETTER DIAGNOSTICS
- ACCESS TO DIAGNOSTICS, INCLUDING DRUG SUSCEPTIBILITY TESTING

# KEY MESSAGES: TREATMENT

- DEVELOPMENT OF NEW DRUGS THAT ARE:
  - SAFER WITH LESS SIDE EFFECTS
  - REDUCE THE DURATION OF TREATMENT AND INJECTIONS
  - RESEARCH FOR INJECTABLE FREE REGIMEN
  - ARE MORE EFFICACIOUS DRUGS THAT COMBAT RESISTANT STRAINS
  - REDUCE THE BURDEN OF TREATMENT
- SUSTAINABLE POLICIES THAT ENSURE QUALITY DRUGS ARE PRESENT AND DRUG STOCK OUTS DO NOT OCCUR, AND THAT PATIENTS ON TREATMENT REMAIN ON QUALITY TREATMENT FOR ITS DURATION

# PSSSSSSSSSSST ! IT'S AN EMERGENCY!

- PREVENT: DR TB: ONLY (CURRENT) WAY TO PREVENT NEW TB, IS TO TREAT IT!
- SWIFTER: DR TB: **ONLY 20%(1 IN 5) DIAGNOSED**
- STRONGER: DR TB: **LESS THAN HALF CURED (48%) AND** LESS THAN 10% GET TREATMENT.
- SAFER: DR TB: **TREATMENT WORSE THAN DISEASE?**  
SEVERE SIDE-EFFECTS ARE COMMON INCLUDING PERMANENT NERVE DAMAGE, HEARING LOSS, BLINDNESS, ORGAN FAILURE AND EVEN DEATH - ALL DUE TO THE 'TREATMENT', NOT THE DISEASE. WE NEED SAFER TREATMENT!
- SIMPLER: DR TB: **1 NEEDLE & 30 TABLETS EVERY DAY!**
- SHORTER: DR TB: **2 YEARS FOR 1 INFECTION?**

# PSSSSSSSSSSSST ! IT'S AN EMERGENCY!

- SCALABLE: DR TB: **NOBODY IS SAFE UNTIL EVERYBODY IS SAFE. NOBODY IS LEFT BEHIND.**  
LESS THAN 20% OF MDR TB PATIENTS ARE STARTED ON APPROPRIATE TREATMENT.
- SYSTEMATIC: DR TB: **CURE ONE, CURE ALL.**
- SUSTAINABLE: DR TB: **POOR TREATMENT = WORSE THAN NO TREATMENT!**
- STIGMA FREE: **IF YOU BREATHE, IT COULD HAPPEN TO YOU.**  
**IT IS NOBODY'S FAULT, BUT IT'S EVERYBODY'S PROBLEM.**
- SOCIO-ECONOMICALLY SUPPORTED: **CURING ONE, MEANS CARING FOR ALL.**  
**TREAT ME, I'M WORTH IT!** TREATING DR TB IS WORTH IT!
- TREATMENT: **INCURABLE TB? WHAT THEN?**  
FOR SOME TYPES OF TB WE HAVE NO TREATMENT THAT WORKS ANYMORE.  
**TREAT WELL AND TREAT EARLY!**

# OUTREACH AND ENGAGEMENT: DEFINING KEY AUDIENCES

- THE PROJECT WILL ULTIMATELY SEEK TO REACH A WIDE AUDIENCE AND ENGAGE PEOPLE WHO OTHERWISE WOULD NOT BE AWARE OF THE DANGERS OF DR TB IN ORDER TO INFORM THIS POPULATION.
- IN ADDITION TO THIS BROAD GENERAL/LAY AUDIENCE, AND IN ORDER TO ADDRESS THE KEY MESSAGES ABOVE, THE PROJECT SPECIFICALLY TARGETS THE FOLLOWING KEY AUDIENCES:
  - *PROFESSORS, RESEARCHERS, AND STUDENTS AT RESEARCH UNIVERSITIES*
  - *LOCAL, REGIONAL, AND STATE POLICYMAKERS*
  - *LARGE DONOR OR ADVOCACY ORGANIZATIONS (I.E. GLOBAL FUND, GATES FOUNDATION, ETC)*
  - *LEADERS WITHIN COMMUNITIES AND TB SUPPORT GROUPS*
  - *PATIENTS CURRENTLY AFFECTED BY DR-TB*

# OUTREACH AND ENGAGEMENT

- FOR EACH SPECIFIC AUDIENCE, WE HAVE AN:
  - OUTREACH MECHANISM
    - *HOW WILL WE REACH THIS AUDIENCE?*
  - ENGAGEMENT MECHANISM
    - *HOW WILL WE GET THIS AUDIENCE TO INTERACT WITH THE PROJECT?*
  - MEASUREMENT MECHANISM
    - *HOW WILL WE MEASURE OUR EFFECTIVENESS WITH THIS AUDIENCE?*

KEY AUDIENCE	OUTREACH MECHANISM	ENGAGEMENT MECHANISM	MEASUREMENT
<b><i>General/Lay Audience</i></b>	We will reach a broad audience by collaborating with our advocacy and research partners to coordinate a print and social media launch, including op-eds in major publications	We will engage the lay audience through our interactive website, which includes online curriculums and learning materials. Engagement will be measured by number of curriculums completed by the audience	Number of people who complete online curriculums divided by number of people who visit the site ("Curriculum proportion")
<b><i>Professors, researchers, and students at research universities</i></b>	We will reach this audience by combining our own network of researchers with those of our collaborators to identify key researcher in TB and drug resistance	We will engage this audience by providing them with audio/visual materials to integrate into their data-based presentations at conferences and other meetings	Number of researchers that agree to integrate personal stories into their presentations over number of researchers approached ("Researcher proportion")
<b><i>Local, regional, and State policymakers</i></b>	We will reach this audience by working with our larger, global partners and regional partners to arrange meetings and workshops with key decision makers	We will engage with policymakers and health leaders by asking them to write op-eds in leading international newspapers and journals (New York Times, Reuters, etc) supporting improved policies	Number of policymakers that agree to write op-eds in support of improved policies divided by number of policymakers approached ("Policymaker proportion")
<b><i>Large Donor or Advocacy organizations</i></b>	We will reach this audience by working with our current international advocacy contacts to identify and connect us with large scale organizations	We will engage with these organizations by asking them to distribute the project through their online and social network channels, such as guest blogs, social media, and coauthoring op-eds in major online publications	Number of advocacy organizations sharing the project through their channels divided by number of organizations approached ("Donor/Advocacy Proportion")
<b><i>Leaders within communities and TB support groups</i></b>	We will reach this audience by working with clinics and local personnel to identify TB leaders in the community	We will engage this audience by having community leaders organize community meetings that screen project stories and distribute curriculums	Number of completed companion curriculums over the number of people attending the event ("Community Proportion")
<b><i>Patients currently affected by DR-TB</i></b>	We will reach this audience by distributing information through TB clinics in various regions	We will engage this audience by inviting them to visit the website and download information specifically for those going through DR-TB treatment	Number of downloads of materials over number of days information is at clinics times the number of clinics ("Patient proportion")

# EVALUATION

- NUMBER AND BREADTH OF SOCIAL MEDIA PRESENCE
  - E.G. NUMBER OF FACEBOOK LIKES, TWITTER MESSAGES WITH #HUMANSPIRIT, ETC.
- NUMBER OF REGISTERED COMMUNITY EVENTS
  - DIVERSITY OF EVENTS, FROM NEIGHBORHOODS TO NATIONAL MEETINGS
- NUMBER OF CONSTITUENTS ON EMAIL LIST
  - DENSITY AND DIVERSITY OF CONSTITUENTS BASED ON
    - PROFESSION
    - GEOGRAPHY
    - AGE
- NUMBER AND SCOPE OF TRADITIONAL MEDIA HITS
  - NATIONAL DIVERSITY IN NEWS MEDIA (AL JAZEERA, NEW YORK TIMES, REUTERS)
  - TYPE AND TIMING OF MEDIA PRODUCTS (ONLINE, PRINT, TELEVISION)
- A COMPOSITE “CREATIVITY INDEX” THAT CAN BE USED TO SHOW THE SCOPE OF ACTIVITY IN GIVEN LOCATIONS OR WITHIN GIVEN SECTORS.
  - THIS INDEX WILL INCORPORATE MINUTES OF VIDEO WATCHED ON THE WEBSITE, WORDS PUBLISHED IN NON-TRADITIONAL FORUMS ABOUT THE HUMAN SPIRIT, NUMBER OF NEW CHANNELS AND NETWORKS CREATED.

# FUTURE PROJECTS

- ▶ UNMASK STIGMA
- ▶ TB IN HEALTH CARE WORKERS/ INFECTION CONTROL
- ▶ HUMAN SPIRIT PROJECT EXPANSION – SCREENINGS, STORIES
- ▶ KICK TB & HIV – RUSSIA FIFA 2018
- ▶ ASK?

# UNMASK STIGMA



# TB IN HEALTH CARE WORKERS



# THANK YOU!



- VISUAL EPIDEMIOLOGY
- AERAS
- WHO
- TB PROOF TEAM
- GDI SECRETARIAT