



James Natchwey

Extremely Drug-Resistant **TB**

A Toolkit for Stopping
a Preventable Pandemic

RESULTS

action
Advocacy to Control TB Internationally



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About the Partners

▶ **RESULTS and RESULTS Educational Fund (REF)**

www.results.org

RESULTS AND RESULTS EDUCATIONAL FUND are committed to creating the public and political will to end poverty through grassroots action, policy research, and effective advocacy. As both a cause of poverty and an affect of poverty, RESULTS works to be a powerful advocacy voice on tuberculosis (TB), a curable disease that still takes the lives of 1.7 million (largely impoverished) people every year.

How We Create RESULTS

Our model is unique and powerful. RESULTS has been mobilizing a vast network of volunteer citizen activists for almost 30 years. With the support of RESULTS, volunteers educate themselves on the issues, mobilize by focusing on the solutions, and gain skills in getting their voices heard by the media, their communities and their elected officials. Each RESULTS group is supported by staff and volunteer leaders who coach volunteers on many of the skills, issues and activities covered in this toolkit.

There are many ways to participate in RESULTS, from taking an occasional monthly action, becoming an active volunteer or investing directly in the work we do to end poverty here at home and around the world. RESULTS provides an opportunity and entry point for everyone interested in making a difference.

For more information about organizing in the US, please contact Ken Patterson: kpatterson@results.org or, for outside the US, contact Meredy Throop: mthroop@results.org.



▶ **The ACTION Project**

www.action.org

RESULTS is also part of the international ADVOCACY TO CONTROL TUBERCULOSIS INTERNATIONALLY (ACTION) PROJECT, working to mobilize greater financial support to treat and prevent the spread of TB, and to change the policies that stand in the way of universal access to TB treatment. It is only a lack of political will that allows TB to claim more lives than any other infectious disease after HIV/AIDS. Since its inception in 2004, ACTION partners have mobilized over U.S. \$554 million in new resources to fight global TB. ACTION is comprised of RESULTS branches in the US, Canada, Japan and the UK as well as The Kenya AIDS NGOs Consortium (KANCO), Global Health Advocates in India and Avocats pour la Santé dans le Monde in France. Please visit www.action.org to learn more about TB and get involved with the ACTION project.



▶ **XDRTB.org**

XDRTB.ORG is an extraordinary effort to tell the story of extremely drug-resistant tuberculosis (XDR-TB) and TB through powerful photographs taken by James Nachtwey. Photographer James Nachtwey has been covering war and human rights stories for 30 years, traveling from Northern Ireland to Iraq, from the orphanages of Romania to the deadly killing grounds of the Sudan. He knows the power of news photographs to raise awareness and make real change. In 2007, he was awarded the TED (Technology, Entertainment, Design) Prize, which comes with \$100,000 and one wish to change the world. The TED Prize is a collaboration of individuals and companies who step up and generously give their time, support and resources to make these wishes come true. These photographs and this project are James Nachtwey's wish. Learn more about James Nachtwey and the TED Prize and the conference that started it all, TED, at www.xdrtb.org.



Welcome to the XDR-TB Toolkit brought to you by RESULTS, the ACTION Project, and XDRTB.org

The goal of this kit is to give you the tools you need to take action in your community to fight TB. In this kit you'll discover ways to best leverage the media, organize in your community, and engage elected officials in the TB crisis. We can only defeat TB if we change the actions of decision-makers—from your local elected MP (Member of Parliament) or Member of Congress to the presidents of the wealthiest countries in the world to the health ministers of highly affected nations. Won't you join us? This kit was designed by advocates from RESULTS—a grassroots advocacy organization with local groups in communities throughout the US, Canada, Mexico, UK, Germany, Japan, and Australia. Volunteer RESULTS partners have won billions in funding for health and poverty and changed major policies—all through taking collective action from their own homes and communities. As such, it has a decidedly “Northern” bent—though we hope that you can adapt these tools for use in your own community.

The TB Epidemic

Many people consider TB a disease of the past. In reality, over 2 billion people are infected with the TB bacterium; that's roughly one-third of the world's population. Although cheap and effective antibiotics have existed for more than half a century, TB kills roughly 4,400 people every day and more than 1.7 million people annually. This information is shocking — if just \$20 to \$100 per patient could save the lives of the millions of people dying from a curable disease, wouldn't our world make saving these lives a priority?

Well, we haven't. Instead, years of under-funding for basic TB control have led to new, human-made strains of this disease that are extremely difficult and costly to treat, and nearly always fatal in HIV-positive patients. Referred to by some TB experts as “Ebola on steroids,” extensively drug resistant TB (XDR-TB) is resistant to first- and second-line TB drugs. One infected person who laughs, coughs, or sings, can result in its transmission. Since its first reporting in 2006, XDR-TB has been confirmed in 49 countries, including all G8 member states — and that may just be the tip of the iceberg, as few countries in Africa have the laboratory capacity to even detect XDR-TB, let alone track and treat it.

SO, how can we change this? The answer? **You**. By increasing awareness and attention to this neglected crisis, you can make a solid impact. Your leadership is needed to mobilize both the political will as well as new resources critical to reversing this global threat and preventing its further emergence. This guide will provide you with the resources necessary to begin educating your communities, media, and elected officials about the threat of drug-resistant tuberculosis so we may finally make it a priority.



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I. Background on TB and XDR-TB

TB Infection and Transmission

TB bacilli are expelled into the air when a person with tuberculosis coughs, sneezes, laughs, or even sings, and are then inhaled by people in the surrounding area. When the bacilli reach the throat or lungs, a latent TB infection (LTBI) occurs. If left untreated, 5-10 percent of people with LTBI develop infectious, “active” TB at some point in their lives, and will typically infect others at a rate of 10-15 people annually unless they’re treated.

TB is a Cause and a Consequence of Poverty

People living in conditions of poverty (overcrowding, malnutrition, poor ventilation, etc.) are more susceptible to falling sick with TB and most likely lack access to detection and treatment services. 95% of people with TB live and die in the developing world.

More than 75% of TB-related disease and death occurs among people between the ages of 15 and 54 — the most economically active people—hampering their ability to help families, communities, and country break free of poverty. TB’s economic impact on families is devastating. Families often sell what few assets they have to secure even partial treatment, and the income of 15 years will be lost if this person dies. Additionally, children may be removed from school when they contract TB, or to help provide care when family members become sick.

Global Efforts

The international response to TB is guided by a business plan called the Global Plan to Stop TB 2006-2015. The Global Plan aims to reduce global TB incidence by 2015 in line with targets set by the Stop TB Partnership and the Millennium Development Goals. The Global Plan also identifies resources needed to reverse the spread of TB and prevent 14 million TB deaths by 2015. The centerpiece of TB control is called Directly Observed Treatment, Short Course (DOTS), which includes the following 5 elements:

- Political commitment with increased and sustained financing
- Case detection through sputum smear microscopy
- Standardized treatment, with supervision and patient support
- An effective drug supply and management system
- Monitoring and Evaluation and Impact Measurement

Global TB Burden

The World Health Organization (WHO) declared TB a global health emergency in 1993. In spite of this, the following problems still persist:

- One-third of the world’s population has a latent TB infection.
- Over 9 million people develop active TB infection each year.
- TB causes 1.7 million deaths each year — more than any other curable infectious disease.
- TB is the world’s leading infectious killer after HIV/AIDS, and is the leading infectious cause of death among persons living with HIV/AIDS (PLWHA).

DOTS Successes

- **DOTS produces cure rates of up to 95 percent, even in the poorest countries. Proper DOTS treatment is essential for preventing deadly drug-resistant strains of TB.**
- **DOTS is one of the most cost-effective health interventions in existence. The World Bank determined DOTS’ economic benefits exceed the costs by a ratio of 10:1.**
- **TB is curable in the vast majority of cases, with a full course of drugs for a standard case costing as little as \$20 in developing countries.**

Drug Resistant TB

Multi Drug-Resistant TB (MDR-TB)

MDR-TB is a form of TB which is resistant to at least Isoniazid and Rifampin — the two most powerful and widely available anti-TB drugs. MDR TB is caused by inconsistent or incomplete treatment for regular TB in a patient, and can be transmitted to healthy individuals just like regular TB. An estimated 489,000 MDR-TB cases emerged in 2006, or about 5 percent of total new TB cases for the year. There are a variety of reasons drug-resistant TB occurs, including:

- Incorrect drug prescription or mismanaged treatment
- Unreliable drug supply
- Inconsistent patient use of medication or early discontinuation of treatment, often because they begin to feel better, suffer unpleasant side effects, or have competing priorities such as securing food or shelter.

Treatment for a single case of MDR-TB is complex, can take up to two years, and is as much as 3,000 times more expensive as a case of regular TB.

Extensively Drug-Resistant TB (XDR-TB)

XDR-TB is resistant not only to Isoniazid and Rifampin, but also to critical second-line drugs normally used to treat MDR-TB. Currently, most XDR-TB cases are virtually untreatable. XDR-TB is a human-made disease and entirely the result of improper TB treatment and management. The U.S. Department of Homeland Security (DHS) has identified XDR-TB as an “emerging threat to the homeland.” Thus far,

- XDR-TB has been identified in 49 countries as of June 2008.
- Because many countries lack laboratory capacity to test for resistance, XDR-TB is widely under-reported.
- XDR-TB patients have an 85 percent mortality rate. In some sampled populations, XDR-TB has had fatality rates approaching 100 percent.
- Current methods of drug-resistance testing typically take 6 to 16 weeks to get results. However, a new form of DNA test just becoming available has reduced the testing time to as little as two days. Under the older form of testing, half of patients with drug-resistant TB die before the disease can be accurately diagnosed and an appropriate drug regimen prescribed. It is imperative that the new test be widely distributed globally, in order to reduce wait time for results and implement effective treatment in a timely fashion.
- XDR-TB need not be a death sentence. With early, early diagnosis and aggressive treatment with the right combination of drugs, countries with good TB control programs have demonstrated that a cure rate of 50 percent is possible.



“XDR-TB sounds a clamorous warning: without the political will to control TB, we will not only fail to defeat HIV but may enable the rise of an incurable, airborne disease.”

— Archbishop Desmond Tutu

TB and HIV/AIDS: The Dual Epidemic

TB is the leading cause of death among people living with HIV/AIDS (PLWHA) in developing countries. Without TB treatment, 90 percent of PLWHA die within months of developing TB. With TB treatment, the lives of PLWHA can be extended 2-5 years, even without access to HIV antiretroviral therapy. TB is an opportunistic infection, and because HIV infection severely weakens the immune system, an HIV-positive person with a latent TB infection is 50 times more likely to develop active TB than someone who is HIV-negative.

However, the standard century-old TB diagnostic test (sputum smear microscopy) does not effectively diagnose tuberculosis in PLWHA and TB treatment cannot always be taken with antiretroviral HIV therapy. Furthermore, while TB clinics have scaled-up cross-testing their patients for HIV, reports suggest that only 1 percent of HIV-positive patients worldwide have been screened for TB.

In order to accurately and effectively diagnose and treat those with TB-HIV co-infection:

- New diagnostics and drugs must be developed that can safely and effectively diagnose and treat TB in those co-infected with HIV
- Laboratory capacity must be scaled up in developing countries so TB can be quickly and accurately detected
- Infection-control measures must be put in place in order to prevent HIV patients from becoming infected with TB in clinical settings
- HIV clinics must routinely offer screenings for TB to every patient seeking HIV/AIDS testing and treatment.

The most recent WHO report on drug-resistant TB found that MDR-TB appears to be associated with concurrent HIV infection. The spread of drug resistant strains of TB is undermining progress in the fight against HIV/AIDS, as XDR-TB spreads quickly and is highly lethal among those with HIV.

New Resources and Political Commitment are Desperately Needed

- It is lack of political commitment and funding that keeps TB a leading global killer. Resources available to adequately tackle the disease have long been insufficient. The World Health Organization estimates that it will cost approximately \$6.7 billion annually to reverse the TB epidemic. For 2008 alone, WHO projects a \$2.7 billion funding gap.
- XDR-TB demonstrates the desperate need for new drugs and diagnostics. No new TB drugs have been developed in 40 years, no effective TB vaccine exists, and the standard diagnostic test has changed little in over a century. Investments in research and development for new TB tools represent just one-tenth of investments for HIV/AIDS tools.
- TB programs must be strengthened and expanded to prevent drug-resistance; surveillance must be strengthened to identify where MDR- and XDR-TB already exist, particularly in Africa.
- MDR/XDR treatments must be scaled up to meet the emerging threat.
- Due to the high risk of death for those co-infected with HIV (even those on ARVs), XDR-TB threatens to reverse progress made against and undermine billions invested in HIV/AIDS. It has taken unprecedented amounts of political will and resources, both globally and at country level, to scale up access to ARVs, especially in Africa. Lives saved by AIDS program scale-up are becoming casualties of an XDR-TB epidemic.
- To save 14 million lives and reach the Millennium Development Goal target for TB by 2015, the world must invest over \$57 billion from 2006-2015.

II. Outreach to the Media

A) Three Ways of Engaging the Media

The following are some of the main ways for approaching and engaging the media. To be most effective in your media advocacy activities, you'll want to DROP NAMES! First, specifically mention the name of the policy maker or agency that should take action. Second, specify where increased TB control funding should be directed, such as the budget of your country's national TB control program, the Global Fund, the Global TB Drug Facility, or your country's bilateral (country-to-country) development assistance initiative for TB. By doing so, you will greatly increase the likelihood that these people or institutions will see this media coverage directly. And finally, if you get published, make sure to send a copy to your member of congress/parliament, as well as to RESULTS (results@results.org) so we can track the global efforts to fight TB.

Be assured, anything in the news mentioning your congressional or parliamentary members will be read the very same day by their senior staff — and likely by the members themselves. Elected officials are sensitized to the views and opinions of their constituencies who hold the power to reelect them. Therefore, those who understand the media and know how to work with editors and journalists potentially possess a great deal of political power.

1. Letter to the Editor about Drug-Resistant TB

Newspapers and magazines have a “letters page” that gives readers the opportunity to express their view or correct previously published information they feel to be inaccurate or misleading. Letters are widely read and provide a good opportunity to promote your cause. They should be short, focused and well written. A letter should aim to make one main point and end on a challenging note, with a call to action. Letters can also be signed by a number of signatories who represent various organizations or interests in order to increase impact. If you are responding to an article carried in a daily newspaper, it is important to e-mail, fax or deliver your letter to the paper within a couple of days and refer to the article about which you are writing. Check your paper's opinion pages or website for guidelines on how to submit a letter.

What to include in your letter:

1. Introduce the topic by connecting your letter with another story that has run recently in the paper — it can be about other threatening diseases, homeland security, poverty or anything with which you can make a connection. If there is no appropriate article, then think of a recent event or happening — nationally or preferably locally — that you can connect with the threat of drug-resistant TB.

2. Pick out a couple of key points to highlight from the “Background” or “Appendix” section of this toolkit, such as:

- Extensively drug-resistant TB (XDR-TB) has now been found in 49 countries, including the U.S. and Europe.
- Drug-resistant TB is flourishing because the world has failed to adequately detect and treat normal TB. It is entirely human-made.
- TB is the number one killer of people with HIV/AIDS. Drug-

resistant TB threatens to undermine all the good work being done to stop AIDS.

- The extent of the problem could be grossly underestimated, as most African nations lack the capacity to test for drug-resistant TB, especially XDR-TB.

3. Assert that strong commitments are needed from governments to fight drug-resistant TB. Call upon your elected officials to take a stand against TB — drop names!

4. Keep it short! The ideal length is about 150 words. Letters over 500 words will probably not be considered.

5. A letter to the editor is an important tool in your media toolkit. Politicians and government agencies routinely clip and circulate letters to the editor as an indicator of what is important to their constituents. If your letter is printed, send a copy to the offices of your Member of Congress/Parliament/Diet!

Sample Letter to the Editor

(This is just an example. Look for a hook in your local paper and for appropriate talking points from the “Background” section of this toolkit.)

To the Editor:

The story “Border Security” that ran on October 5 did not touch on one critical threat – the spread of dangerous, extensively drug-resistant forms of tuberculosis across borders. A recent WHO report states that extensively drug-resistant TB (XDR-TB) has now been found in 49 countries, including all G8 countries. Drug-resistant TB is flourishing because the world has failed to adequately treat normal TB. And in our interconnected world, TB anywhere is TB everywhere.

Unfortunately, nothing can be done at the borders themselves to stop TB – the disease can be undetectable and is easily spread through the air. But much can be done through increasing resources to fight this curable disease. With early diagnosis and aggressive treatment with the right combination of drugs, countries with good TB control programs have demonstrated that a cure rate of 50 percent is possible. Cost-effective infection control measures could reduce the spread of XDR-TB by 50 percent. There is a path to beating back drug-resistant TB, and our government needs to provide the resources to follow this path. I encourage all readers to visit www.action.org to get involved in the fight against TB.

Sincerely,

Your Name

2. Op-eds

Most newspapers print opinion editorials (op-eds) or guest columns. *An op-ed is an expression of opinion rather than a release of news.* Although style varies according to different countries, an op-ed tends to be lively, provocative and sometimes controversial. They provide a very effective way to register concern about TB to policy-makers and to inform communities about why they should care about controlling the disease. Op-eds are usually 600 to 1,000 words. It is best to call the newspaper first and request their guidelines for submitting an op-ed. If possible, speak to the appropriate editor to alert them that you intend to submit an op-ed and briefly explain the importance of the issue.

3. Editorial Meetings

An editorial is a statement or article written by an editor or collectively written by an editorial board of a newspaper to represent the newspaper’s official positions on issues. It expresses an opinion rather than simply objectively reporting the news. Gaining the support of a local newspaper regarding your issues can leverage your influence on policy makers and your community. An editorial statement from your leading local newspaper, addressing the responsibilities of your elected officials, is perhaps the most powerful form of media advocacy. You should approach the editorial board members of your local paper and offer to provide them an editorial briefing on the global TB epidemic. If you can arrange an editorial board meeting, this will provide you with an excellent opportunity to gain the editorial support of a newspaper which, in turn, can be very influential in shaping political decisions. Begin by doing your homework prior to the meeting. Profile the kinds of editorials that appear in the paper and the position they tend to take, particularly in relation to international issues. Arrive armed with facts and figures that are relevant to the newspaper’s audience. Make a persuasive argument that their readers should be concerned about the global TB epidemic. Make clear why specific elected officials from your area have influence on these matters. Be ready to answer any questions the editor might have. After the meeting, research and provide any further information requested.

B) Media Basics and PRESS: Building a Relationship with Media Contacts

PERSISTENCE: There's a fine line between persistence and pestering, but realize that just like our parliamentarians or members of Congress who see thousands of bills in any given year, editorial and health writers are faced with similar challenges and many potential editorial topics. Remember to stick to your guns when the phone calls or e-mails are not returned or the answer is "no" for the tenth time on getting an editorial published. Keep calling, keep asking, keep offering them information that they will realize they want and need.

RELATIONSHIP: Fostering and building good working relationships with editorial and health writers is key to our success in generating media on a consistent basis. When we are working on developing our relationships with the media we should act with as much rigor and intensity as we do when we are developing relationships with our elected officials.

EDUCATION: Good reporters and editorial writers are always looking for a fresh scoop to follow. Our job is to provide them with current, accurate, up-to-the-minute information on our issues. Don't expect that your writer will know more than you on any given subject surrounding hunger and poverty; in many cases you may be far more educated on these matters than they are.

SENSITIVITY: Writers, particularly at a daily newspaper, are busy! Be sure to ask up front if they have a moment and be prepared to reschedule if necessary. Be sensitive to their moods and possible gruffness and don't take it personally. Stay polite and on message. If they seem uninterested, ask if there is a better person to direct your information to.

SUCCESS: If you follow these steps you are well on your way to generating media in your community! You may not get your writer on this particular media call or generate an editorial, but every contact you make pushes your relationship further and further ahead.



Good reporters and editorial writers are always looking for a fresh scoop to follow.

Sample Letter to Elected Official

Dear Elected Official:

Please take the time to watch this important slideshow about tuberculosis, a disease that kills 1.7 million people every year. Stopping TB requires your leadership, and the time has never been more urgent. I used to consider TB a disease of the past, but James Nachtwey's powerful photos helped me realize that nearly 2 million people die every year from this curable and preventable pandemic. TB is the leading killer of people living with AIDS, and now the emergence of extensively drug-resistant tuberculosis (XDR-TB) threatens to roll back progress made and billions invested in the fight against HIV/AIDS. Called "ebola on steroids" by some TB experts, XDR-TB is entirely human made, resistant to many first- and second-line TB drugs and is extremely expensive and difficult to treat. The first reported outbreak was in 2006 in South Africa, where it killed 52 of 53 patients diagnosed – half of them within 16 days. XDR-TB has since been confirmed in 49 countries, including the United States and the entire roster of G8 member states.

The slideshow is a compilation of powerful photos documenting the neglected XDR-TB crisis shot by globally renowned photojournalist James Nachtwey. By viewing this slideshow, you too can witness how inconsistent and under funded TB treatment is not only costing millions of lives annually, but also resulting in drug resistant forms of tuberculosis that are more expensive and sometimes nearly impossible to treat.

More commitment and political will is needed to increase support and resources for fighting this global and domestic health emergency and to meet the goal of halving TB prevalence and deaths by 2015. I hope you are willing to take a strong stand against tuberculosis, a completely curable disease that has haunted humanity for too long. Please do all that is in your power to ensure the necessary political will and funding levels to stop TB. I look forward to talking with you and your staff personally about the slideshow and how we can work together to fight TB. I will follow up with your office in two weeks.

Sincerely,

Your Name

Address

Telephone number and email address

III. Outreach to Elected Officials

A) Send a Letter and Powerful XDR-TB Slideshow to Your Elected Officials

Let your elected official know about the tragedy of tuberculosis and drug-resistant TB through a moving slideshow. After watching the slideshow at www.action.org or www.xdrtb.org, you can email the link to your elected official and then write him or her a letter, calling for a bold commitment to fight this global crisis.

In Your Letter

1. Raise your concern that TB has re-emerged as a global pandemic, particularly due to recent increases in multidrug-resistant TB (MDR-TB), which has been documented in almost every country worldwide, and extensively drug-resistant TB (XDR-TB), which has been found in 49 countries to date.
2. Point out that this hits those living in poverty hardest, but also poses a threat to health security across national borders with globalization
3. Acknowledge their support if your Elected Officials have backed the Global Plan to Stop TB. Visit: <http://www.stoptb.org/partners/default.asp?sort=3&alphaIndex> to see who has pledged support to the Global Plan.
4. Ask them to do all they can to increase support and resources for fighting TB and drug-resistant TB, in order to meet the goal of halving TB prevalence and deaths in the region by 2015, compared with 1990 levels.
5. Request a response and a meeting to further discuss the issue and how you can support your Elected Official.
6. Send a copy of your letter to results@results.org and let us know if you get a response!

B) Ask a Question at a Town Hall Meeting or a Candidate Forum

Going to an event where your elected official is speaking and asking questions is an excellent way to thank them in public, call them to action on a particular issue, or ask them to take a leadership role on the issue of drug-resistant TB.

The media are often at these events and cover the questions asked of the legislator. Media coverage will help influence your official, educate the community in the room, and have it covered by a local paper — a super triple play!

Tips on Attending a Town Hall Meeting or Candidate Forum

1. **Do your homework.** Find out from the local office when and where your official will be speaking or holding a candidate forum.
2. **Prepare questions ahead of time.** Use the EPIC format (see below) to craft your questions. Be confident, considerate and persistent about getting an answer to your question.
3. **Get familiar with the candidates for office.** Ask for a bio and background on candidates from their campaign headquarters, or look for this information on the candidate's website.
4. **Work in teams.** Sit in different areas of the room to maximize your impact. Designate a note taker to jot down all info and promises made by the official. Seek out media after the meeting to talk about TB and drug resistance if they were not covered. Seek out the candidates after the meeting to introduce yourself and follow up on your question, or ask it if you were not able to ask the question during the meeting. Leave the event with a clear plan to follow up with their staff.
5. **Stay on message.** Don't get distracted or angry if your question is blown over. Be forceful in repeating the question and asking for an appropriate response.



Pierre Viot

People are speaking up about TB all over the world, including this TB survivor in Ghana.

C) Meet with Your Elected Official

Meeting and developing relationships with your elected officials and their aides has been one of the key components of RESULTS' success over the last 25 years. You can use these pages to plan and practice for upcoming meetings with your elected officials. If you need information or support in setting up a meeting, please contact us at: results@results.org so we can connect you to RESULTS partners in your region.

Tips for a Powerful Meeting with Your Elected Official

Before the meeting:

1. **Do your homework.** Find out what issues your officials care about and put out as their priorities. You can do this by taking a look at their respective websites, asking their offices for copies of their newsletters, reading up on their biographies, or finding out what committees they sit on (usually available on their website).
2. **Be prepared — practice speaking.** After you create an agenda for the meeting, each person with a speaking part should create a brief two or three minute laser talk for their section and practice it with at least one other person. Be brief, clear and to the point and don't be afraid to show your passion.
3. **Choose a secretary and manager for the meeting.** Choose one person who will be responsible for taking notes and writing down any commitments your elected official made and any follow up that needs to be done after the meeting. Also, choose someone who will "manage" the overall meeting, keeping the group on task and making sure all the requests are covered.
4. **Inspire yourselves.** Prior to the meeting, spend at least a few minutes having each person speak about why he/she cares about this issue and why you are going to this meeting.

At the meeting:

1. **Connect with your officials and their aides.** Establish a personal connection with your official and their aide in the meeting by asking them to share their goals and the issues they care about. Share your own vision and concerns.
2. **Acknowledge your member of Congress.** It is rare that officials hear the words "Thank You" from their constituents. Always thank them for the supportive actions they have taken or just be sure to thank them for taking the time to meet with you. Most likely your point person in the office will be a legislative aide, but be sure to take time to thank them as well. Praising a good legislative aide in front of their boss is always a good thing.
3. **Be concise.** Summarize your request in 5 minutes or less.
4. **Be prepared to summarize opponents' arguments on the issue.** Know the other side of the coin. There may be coherent arguments against what you are asking for. Be prepared and do your homework on any opposition. Have talking points prepared to defend your position. Never attack. If you don't know the answer or how to respond tell the aide or official you will get them further information — it's a great excuse to follow-up and build a relationship with the office.
5. **Don't be a zealot.** Fair, balanced, and thoughtful conversations will keep the door to your official's office open even if you don't find common ground. Always leave with a thank you and a commitment to follow up with relevant information.
6. **Don't be a know-it-all or talk down to an aide.** Aides can be very young and may not know about global poverty issues, including tuberculosis and drug-resistant TB. Our professional-

ism and knowledge can be an example of effective, savvy grassroots lobbying.

7. **Make the issues real.** Sharing a story will put a human face on the issue and get your official and their staff emotionally involved in TB and your meeting. One of the most powerful ways we can advocate for tuberculosis is to have someone speak who has been directly affected by TB and can tell their own experiences. Another possibility is to tell the story of a specific family or to show a video during your meeting that puts your legislator in the shoes of others for a few minutes and makes the issues real. Some of these stories and video clips can be found at www.action.org. This is a great opportunity to use the slideshow of James Nachtwey's photos to reinforce your points!
8. **Paint the big picture and the small picture.** For example, one person could tell their story about how TB has affected her/him personally (the small picture); then, someone else could flesh out the current national or global statistics and impact of TB and drug-resistant TB (the big picture).
9. **Make specific, clear requests and ask for an answer.** Often, the main reason groups have unsatisfactory meetings is that their requests were not clear and specific enough. Your officials need to know what you want them to do (what bill you want them to sponsor, what other official you want them to speak to, how you want them to vote). However, in addition to the specific requests you bring, don't be afraid to ask them what else they think they can do on TB (whether they say yes or no to your original request).
10. **Carefully record any questions, objections, promises or concerns.**
11. **Know your next steps.** In the meeting, ensure that the next steps for follow up are clear (what your group will do next, what the legislator/aide will do next) and that you know which aides to contact for follow up. After the meeting, send a prompt thank you note and follow up on requests with the aide.

After the Meeting:

1. **Plan for follow up.** During the meeting set a specific timeline for follow up with staff. Be sure to have someone record your plan for follow up.
2. **Send a "Thank You" letter.**
3. **Follow up.** Be sure to follow up with the appropriate aide(s). Without follow up, your effort in scheduling a meeting and speaking powerfully about our issues could be wasted.



RESULTS activists from Michigan shared the story of TB-HIV survivor Joseph Jeune with Rep. Joseph Knollenberg during a meeting in his office in Washington, D.C. "The photos of Joseph are such a good example of what a difference treating people for TB and AIDS makes," said Yvonne Wyborny, shown holding a picture of Joseph after treatment.

IV. Community Outreach

If you live in United States, Canada, Mexico, Kenya, Japan, France, India, or Germany you can volunteer with a RESULTS or ACTION partner! Visit www.action.org to get connected. To find a local RESULTS group, please contact us: results@results.org.

A) Reaching Out to Community Groups and Officials

Why focus on networking? There is an Ethiopian proverb that sums it up pretty well: “When spider webs unite, they can tie up a lion.” By working with community groups and key local officials, we can leverage political clout for our campaigns AND build the profile of our work in your own cities and towns.

Identify local organizations, groups of activists, media, officials and influential members of your community that you can contact. (The suggestions below are just suggestions. Think creatively!)

COMMUNITY ORGANIZATIONS: Check your yellow pages under “Social Service Organizations” for specific names of agencies and organizations and for other ideas.

POLITICAL ACTIVISTS: Think of people involved in politics, party or otherwise — volunteers, state officials, or county officials, etc. who might be too busy to be advocates themselves but might have ideas for people who might be involved.

FAITH COMMUNITIES: Many people communities of faiths have a strong history of involvement in social action.

COLLEGES/UNIVERSITIES: These can be a good source of partners who are not overly committed with community activities. It’s important to have a staff or faculty member who would take the lead in coordinating activity of students.

HIGH SCHOOLS (AND MIDDLE SCHOOLS): Schools are ripe with spirit and creativity. Again, a teacher-coordinator is important.

OTHER FOLKS: Perhaps the most important source of partners is people you know, regardless of their affiliation or professions. Think about the people you care about, the people in your life, the people who share your interests and concerns.

B.) Speak to a Local Community Group, Church or School About XDR-TB

1. **Pick Your Audience.** Possibilities include: Social action committees, political organizations, student groups and faith/religious groups. See Activist Milestone 12: Building a Grassroots Community Network at www.results.org.
2. **Your Topic: TB and Drug-Resistance:** You can offer to facilitate an issue briefing and train people to take action. Online at www.action.org we always have something you can do to fight TB—be it letters, media outreach, etc. For more information on leading an advocacy training, see: Sample agenda for speaking powerfully workshop; Sample agenda for a media training workshop; Sample agenda for a basic lobby training workshop; Example of an advanced lobby workshop at www.results.org
3. **Identify Your Target and Contact:** Call the organization you chose and ask to speak to the person who handles outside speakers. Have your topic already decided, but be flexible if you can tailor your talk to what they need. Set your date.
4. **Draft and Practice Your Presentation:** Introduce yourself and the work of your local group. Introduce them to the scope of the problem of TB. Focus on stories rather than numbers. Educate them about the solutions with specific examples from the field and legislative successes. Call them to action by letting them know how they can become more involved and always offer them an action to take at the end of the meeting.
5. **Deliver Your Presentation:** Bring hand-outs such as background materials or an easy action alert. Bring a sign-up list. Deliver your presentation and answer questions. Stay after your presentation to engage with people who want to talk further.
6. **Follow Up:** Contact people who asked to be contacted. Thank the person who scheduled your speaking appointment.

V. The Power of Public Speaking

Create and Deliver an EPIC Laser Talk

Learning how to speak powerfully about our issues is one of the most important tools in our activists' toolkit. Use this section of the training to teach participants how to use EPIC laser talks and writing format to speak and write powerfully when calling journalists who have very little time to speak or writing to editors who are inundated with letters everyday.

E FOR ENGAGE YOUR AUDIENCE

Here, you want to get your listener's attention with a dramatic fact or short statement. Keep this opening statement to one sentence if possible. For instance, you could say:

"I was thinking this morning about how the \$12 that I spent on dinner last night could save a life. That is the cost of treating someone with tuberculosis in the developing world. Then I thought about what \$100 million could do."

P FOR STATE THE PROBLEM

Here you present causes of the problem you introduced in the first section. How widespread or serious is the problem?

"\$100 million is the amount that the Senate recently added to the 2006 spending bill for the Global Fund for Aids, TB, and Malaria through an amendment. This brings the total for the Global Fund in the Senate to \$600 million. The House allocation for the Global Fund for 2006 is only \$400 million."

I FOR INFORMING ABOUT SOLUTIONS

Here you inform the listener about a solution to the problem you just presented. Develop your solution by examples of how and where it has worked, how it is proven and cost-effective and how it has benefited the poorest. You could cite a recent study or report or tell a first-person account of how the solution has impacted you or others you know.

"This year our government is falling behind on its "fair share" contribution to the Global Fund by \$300 million. The 3 treatable diseases addressed by the Global Fund kill over 6 million people each year. Tuberculosis alone kills 2 million people and preys particularly on people who are HIV positive. You can imagine how devastating this is on the African continent where 25 million people are HIV positive and in India where over half of the 1 billion people who live there carry the tuberculosis bacterium. In fact, TB has become such a crisis in Africa that on August 22, health ministers and global health officials will meet in Mozambique to declare TB a health emergency on the African continent."

C FOR THE CALL TO ACTION

Now that you've engaged your listener, presented the problem and informed them of a solution, what do you want them to do? Make the action something specific so that you will be able to follow up with them and find out whether or not they have taken it. Present the action in the form of a yes or no question.

"I would like to invite you to a special media call on August 26 to learn more about the TB health emergency in Africa. There will be health and policy experts on the call to explain the declaration and to answer questions about why this is important to Americans. The call also make it clear why we need to expand the funding available for TB from the legislature when they meet in September to finalize the 2009 budget. Can I count on you to listen in on this call?"

Delivering Your Laser Talk

Any good musician or actor knows you would never go on stage without rehearsing first, and it's no different with public speaking. Taking the time to educate ourselves about the issues, writing a laser talk and then practicing our speaking skills is the most powerful tool in our activists' toolkit. (NOTE: you can download a fuller toolkit at www.results.org) Being a good advocate requires that we get out of our comfort zones and commit ourselves to practicing speaking the issues in front of others. The first time you use your laser talk with an elected official or the media, you'll never go back to winging it again.

It's important to speak to the other person instead of reading the information word for word. You can, however, refer to notes at first. And you'll want to strive to keep the talks short — no more than two minutes. As you speak the information, you'll discover where you need more practice or where you may want to change a part of it. These talks will develop and change as you learn new information over time, so be flexible and always keep on the lookout for interesting facts to update your talks.

Tips for Delivering your EPIC Laser Talk:

- **Practice** your laser talk several times before practicing in front of another person.
- **Memorize** as many of the details as possible.
- **Choose a member** in your group that you feel safe practicing with.
- **Identify your audience** — for example an elected official or a new advocacy partner.
- **Deliver your talk without stopping**, even if you have a few stumbles along the way. The more you practice the better you will get.
- **Once finished, critique yourself.** Pick two things that you liked about the talk and one thing you would like to improve upon.
- **Listen with an open mind and ear** for learning how to make your talk better when your partner gives you feedback on your delivery.

Tips for Listening to an EPIC Laser Talk:

- Ask the person delivering the talk to explain to whom they are targeting their talk.
- Listen intently to the talk trying to pick out different sections of the EPIC format.
- Did they engage you up front? Did they describe the problem and its solutions? Were you inspired by a clear call to action?
- Ask the person delivering the talk to critique their talk if they forget.
- Tell the person delivering the talk two things that you really liked about the talk and one thing that you think they could improve upon.

Any good musician or actor knows you would never go on stage without rehearsing first, and it's no different with public speaking.