

Press Conference Report

EugeneBell is in fact two separate, independent organizations that combine their resources to fight tuberculosis in the DPRK (North Korea). In North Korea we are known simply as 'EugeneBell'. Our primary focus is multidrug-resistant tuberculosis, which cannot be treated with inexpensive regular TB medications. All of our patients have failed treatment and need special, expensive MDR-TB medications if they hope to live. Although most of our funding for MDR-TB work has come from the private sector and although we have never become involved in politics, this spring EugeneBell suffered a serious disruption in its program.

Our first challenge was a delay in the issuance of our export permit. Since we purchase most of our medications, diagnostic equipment and other supplies in South Korea, we face a major medical emergency if our medications do not arrive on time. To treat multidrug-resistant tuberculosis, patients must take medications for 18-24 months. Disruption in medication shipment can result in patients not receiving a constant supply of medications. This would mean instead of getting better, they would develop increased drug resistance, fail treatment, and die, after spreading an even more dangerous form of TB to their families and associates. Finally, after intense negotiations with ROK authorities, our shipment was released and we were able to send our regular spring shipment in March. Although our spring shipment was delayed for one month, we were able to work with PRC authorities to speed up its transit through Dalian, making it possible for our medications to arrive at our twelve treatment centers in North Korea before our patients ran out of medications in April.

Our second challenge was a delay in issuing North Korean visas for our spring delegation. Our program must run on an exact schedule where all 12 treatment centers receive six-month supply of medications on each delegation visit. Because delegation members meet all patients and oversee admissions and discharges, delays in delegation visits by more than a week make it problematic for us to admit new patients during that visit. At the beginning of this year, we had approximately 1,500 MDR-TB patients under treatment. We had planned to admit 500 new patients this spring and 500 patients this fall. But because we were not able to visit on schedule this spring, we could not enroll the 500 new patients we had hoped to enroll this spring.

Having faced major obstacles in the ROK and the DPRK this year, I began to wonder if it was not time to close EugeneBell. Unlike government-to-government funding or international organization-to-government funding, EugeneBell does not have a fixed budget from year-to-year. Instead, we rely on voluntary donations by people who are deeply committed to our program. Unless our program can transcend politics and tensions, maintaining a responsible treatment program becomes impossible. This is a question that is relevant not only for EugeneBell, but for all non-governmental contacts with North Korea. Ultimately, the Korean people South and North must decide if vital private sector exchanges can be protected from the chronic tensions on the Korean peninsula.

My recent trip to Pyongyang and this visit to Seoul have been attempts to learn whether or not our treatment program could be shielded from future scheduling and shipping disruptions. After my return to Seoul from meetings in Pyongyang we have been meeting with ROK government officials in hopes of resolving our purchasing & shipping issues. We have also begun a conversation with US government authorities in Washington to explore another sanctions-related issue. We should know more about EugeneBell's future at the

conclusion of these conversations.

This special press conference was scheduled to report on progress so far:

TRIP TO PYONGYANG

From every indication we received on our recent trip to Pyongyang, North Korean health authorities, local caregivers and patients are anxious that our program continue. When we were not able to come according to our agreed schedule this spring, we had asked that no new patients be admitted in our absence, and that all the medications we sent this spring be used to insure that all registered patients were able to finish the program. The North Korean Ministry of Public Health fully complied with this request. I found that all the medications left over from what was distributed this spring to registered patients were stored in our warehouse, and I received a comprehensive report on just how much had been distributed to registered patients at each of the 12 treatment centers we support. In our meetings with MoPH authorities, we were promised a regular schedule from now on. To avoid times of particular tension on the Korean peninsula, we agreed that our visits should take place in November and May instead of October and April.

In response to this encouraging news from the North, EugeneBell has taken the following actions:

1. We have already applied to North Korean authorities for approval of our autumn delegation's visit beginning early November.
2. We have contacted the companies that produce our medications and supplies and have asked them to help us make an emergency shipment in time for this autumn's visit. I was delighted to learn that our suppliers see no problem with the manufacture and shipping of medications and other supplies by the end of September. Our program is organized into three 'kits'; a) a 'Treatment Kit', b) a 'Delegation Supply Kit, and c) a 'Capacity Building Kit'. Normally it takes five months for us to get ready for a visit but we only have 2 1/2 months before our next visit. Because we have received an export permit, we can now enroll all 1,000 new patients we planned to enroll in 2016, thanks to the good will of the ROK government, our suppliers, and Korea's famous 'hurry up culture.'
3. As soon as I arrived in Seoul I applied for an export permit for enough medications and supplies to enroll approximately 1,000 new patients in November. We also hoped that we could get the necessary support to expand our program in order to enroll even more new patients next year (2017).
4. We have ordered four new GeneXperts so that we can have 10 available by this autumn. This would make it possible for us to process more sputum at each center.

VISIT TO SEOUL

I am happy to report that our export license for shipping medications for this autumn has been approved. We are still waiting, however, for permission to expand our program.

IT IS TIME FOR A FRANK DISCUSSION OF UNDERLYING PROBLEMS.

Sadly, we must face the facts: some of our patients have died and others will die because our program was delayed this spring. Nevertheless, EugeneBell's problem this spring is only the tip of an iceberg. Even if we had not faced a scheduling problem this spring, because of our limited capacity we would have been able to enroll only 1,000 new patients in 2016. Based on our experiences this year, we will have to work hard to obtain permission to enroll only 1,000 new patients in 2017. On the other hand, even the most optimistic estimates are that there are from 4,000 to 5,000 new MDR-TB cases in North Korea every year.

So why not expand MDR-TB treatment in North Korea? The cause is the same one that disrupted our treatment program this spring: tensions on the Korean peninsula.

According to an article published in a prestigious US medical journal, EugeneBell's MDR-TB treatment program is doing a good job, considering the challenges we face. While the world average success rate for MDR-TB treatment (including developed countries) is only 48%, several years ago our program reached a success rate of over 75%.

In recognition of this accomplishment, EugeneBell was selected by Partners in Health to implement an experimental program for treating North Korean patients who fail MDR-TB treatment.

This is more North Korea's accomplishment than EugeneBell's for without the enthusiastic support of North Korean healthcare providers, this level of success would have been impossible. Any other country that had achieved this level of treatment success would be offered support from the international community to scale-up MDR TB treatment to make it available nation-wide. (As you can see on our map, our program provides only partial coverage to the western half of North Korea. (The Global Fund program is much smaller.)

Koreans have superstars in medicine as well as in the Olympics, Dr. Kwonjune Seung, the co-author of the WHO field manual for MDR-TB, has developed a plan for expanding our program. In ordinary circumstances, this plan would have received widespread support and funding.

Moreover, the North Korean Ministry of Health has been anxious for some time to expand diagnostic capacity as the first step in creating a nationwide program. Not only have they asked the Global Fund for equipment, but last year they asked EugeneBell to try to find support in South Korea.

We passed this request on to medical authorities in the ROK and as well as to the public but have received no response. Why? The answer is simple: tensions on the Korean peninsula. Here are two important reasons:

1. The international community is reluctant to invest scarce resources in scaling-up MDR-TB treatment in North Korea because it believes the ROK should bear the major burden. And yet, South Korea is reluctant to invest because of sanctions.
2. Major scale-up of diagnosis must be based on GeneXperts. This is the diagnostic tool EugeneBell uses to admit new patients. But unfortunately, while allowing EugeneBell delegations to use GeneXperts, the US government restricts their use in North Korea because of sanctions. EugeneBell's use of our GeneXperts is strictly regulated by licenses. EugeneBell has approached the US government several

times requesting that these restrictions be removed. If we had the support of the South Korean people and government, success would be assured, but because of South/North tensions, we have not been successful so far.

RECOMMENDATIONS

With this press conference, EugeneBell is making its first recommendation to the ROK and US governments on how to address the problem of tuberculosis on the Korean peninsula. We are also issuing a formal appeal to the Korean public. We are not doing this in an attempt to influence politics or policy, but to suggest how current policies that specifically exempt humanitarian assistance could be better implemented.

1. Only by treating all patients can we stop the spread of this deadly disease. To meet the growing crisis in MDR-TB in North Korea, we are asking the Republic of Korea government to consider issuing 2-3 year licenses to ship medications and other supplies, including construction materials for new patient wards; materials needed to expand MDR-TB treatment to all North Korean MDR-TB patients.
2. Only by proper diagnosis can MDR-TB patients be identified. We are asking the US government to lift restrictions on the use of GeneXperts in North Korea so that our machines could be used as part of a nation-wide diagnostic network for MDR-TB.
3. Only by adequate support will all North Korean MDR-TB sufferers have hope for survival. We are appealing to the South Korean people to provide the necessary financial support to expand our current treatment program to cover areas not covered under our current program.

CONCLUDING COMMENTS

Koreans take pride in their tolerance for tensions on the Korean peninsula. Most people believe that they will be OK if there is no war. This is not completely true.

While war on the Korean peninsula would be unimaginably destructive, Koreans should remember that people die because of tensions as well as direct conflict. EugeneBell's experiences this spring clearly illustrate this fact. People have died needlessly because our program was delayed. But as tragic as this loss of life has been, it is nothing compared to the number of people who die annually because MDR-TB treatment is not available nationwide.

By our calculations, Korea suffers approximately ten Sewolho's worth of deaths each year simply because treatment is not available to all MDR-TB patients in North Korea.

In the end, we are all 'in the same boat' with TB patients, no matter where they might live on the Korean peninsula. The sooner we realize this and take appropriate action, the better for us all.