THE POWER OF COMMUNITY ENGAGEMENT IN TB RESPONSE

Stories of Change from Mongolia, Nepal, and Pakistan

ACT! ACTIVISTS' COALITION ON TB ASIA-PACIFIC

APCASO Strengthening community systems. Advancing human rights.

MTC MONGOLIAN ANTI TB COALITION

RISHULI PLUS COMMUNITY ACTION GROUP

ASSOCIATION OF PEOPLE LIVING WITH HIV PAKISTAN

ACT!MN ACTIVISTS' COALITION ON TB MONGOLIA

ACT Nepal Affected Community By TB

ACT! PK ACTIVISTS' COALITION OF TB PAKISTAN

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APCASO
66/5, 33 Tower, Soi Sukhumvit 33
Sukhumvit Road, Klongton Nua, Wattana
Bangkok 10110 Thailand
Telephone : +66 (0)2 044 8800
Email : secretariat@apcaso.org
Website : www.apcaso.org

PUBLICATIONS TEAM
Coordinator: Mangala Namasivayam
Content contributors: Asghar Satti, Uzair Tariq, Ganzorig Munkhjargal, Karishma Banjara, and Mangala Namasivayam
Design and Layout: Rei Neptomos
Translators: Davaajav Khandjav (Mongolian), Sadhuram Sapkota (Nepali), and Abdul Raheem Khan (Urdu)

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ACKNOWLEDGMENT

ACT!AP and APCASO would like to extend our sincere appreciation to the Global Fund through the Community Engagement Strategic Initiative (CE SI) for always putting communities and key affected populations at the centre of the TB response by providing critical resources to fund the long-term capacity building of TB-affected communities.

We extend our heartfelt gratitude to our country partners: the Mongolian Anti-TB Coalition (MTC), Trishuli Plus, Nepal, and the Association of People Living with HIV (APLHIV), Pakistan for their unwavering support in making this project possible despite challenging conditions in their respective countries. We appreciate their continued commitment to putting communities first and ensuring that the voices and needs of communities remain at the heart of their work.

And finally, our deepest appreciation goes to the members of the Activists' Coalition on TB, Mongolia (ACT!MN); Activists' Coalition on TB, Nepal (ACT!Nepal); and Activists' Coalition on TB, Pakistan (ACT!PK), for courageously sharing their stories, personal journeys, and challenges. We are deeply inspired by their experiences, resilience, and unwavering spirit. We hope their stories will help strengthen the case for placing communities at the heart of health responses and ensuring that policies and programmes are shaped by the lived experiences of communities.

BACKGROUND

The Activists' Coalition on TB Asia-Pacific (ACT!AP) and APCASO successfully implemented the long term capacity strengthening of TB community networks under the Community Engagement Strategic Initiative (CE SI) of the Global Fund from 2024 to 2026. The project was implemented in collaboration with three country partners; Association of People Living with HIV (APLHIV) in Pakistan, Mongolian Anti-TB Coalition (MTC) in Mongolia and Trishuli Plus (TP) in Nepal. The primary objective of the project was to strengthen the capacities of TB survivors and key population to engage in Global Fund and related national processes. Based on consultations with TB-affected communities in these countries, an urgent need was identified for a network to represent the voices of those affected by TB in the national TB response and decision-making spaces. This need led to the establishment of three national TB networks; Activists' Coalition on TB Mongolia (ACT!MN), Activists' Coalition on TB Pakistan (ACT!PK) and Activists' Coalition on TB Nepal (ACT!Nepal).

These nascent TB networks had their work cut out for them. It was envisioned that through this networks, TB-affected communities in these countries would be able to effectively influence national strategic plans (NSPs) and Global Fund program fundings; generate and use data to inform advocacy; hold decision-makers accountable; and ultimately drive quality TB programming in the country by adopting global guidance and sharing best practices. To achieve this, ACT!AP and APCASO supported our partners to conduct tailor-media training and mentoring sessions to effectively build the capacities of these communities. The groundwork and investment of the past three years culminated in a critical payoff during the recent Global Fund Grant Cycle 8 (GC8) processes. These TB networks led the way in ensuring that TB-affected communities actively engaged in the process and that their needs and asks were well-represented in the funding requests.

Another key focus of this phase of the project has been strengthening the organizational capacities of these TB networks to ensure that their influence, relevance, effectiveness, and sustainability extends beyond the project timeline. While these efforts have been challenging due to the current funding landscape and scare resources for civil society and community engagement, there have also been encouraging signs of government support for elevating the voices of TB-affected communities and safeguarding the gains made so far.

This publication captures the experiences and stories of communities that have been part of the TB network journey. It documents the lessons learned and challenges faced in strengthening community engagement within the national TB response. These stories are a reflection of communities that, despite facing challenging situations, remain resilient and continue to fight for a seat at the table to ensure that decisions made about them include them. These are stories of persistence and the unwavering human spirit that keeps us all going.




MONGOLIA

Journey of Community Voice, Leadership, and Impact

From Community Mobilisation to a National Advocacy Coalition

ACT!MN
ACTIVISTS' COALITION ON TB MONGOLIA

MTC
MONGOLIAN ANTI TB COALITION

August 22, 2024



POLICY DIALOGUE BEGINS

A morning meeting with the Advisor to Minister of Health and National TB Program was held. Discussions included UN HLM political declaration on TB, TB policy priorities, domestic and external financing, and stronger CSOs and CE.

September 12 - 13, 2024



COMMUNITY LEADERSHIP TRAINING

36 participants took part in a 2-day training program for TB survivors, CSOs working with KVP, and CHW of MATA. The course covered the Mongolian TB situation, CE, Global Fund financing, CCM and building a community network.

April 3, 2025



ACT!MN COORDINATION COUNCIL FORMED

The coalition's name, vision and mission statement were approved. Three core strategic pillars were identified. Founding members included MTC, MATA, MSDSA, Ulziit-Asar, YouthLead, and Phycological Scenes.

April 21, 2025



REGIONAL COMMUNITY EXCHANGE

Representatives of Trisuli Plus Community Action Group (Nepal), Association of People Living with HIV - Pakistan, and APCASO visited Mongolia to exchange experiences and discuss the TB response with Mongolian national stakeholders.

April 22, 2025



ACT!MN OFFICIALLY LAUNCHED

"TB-Free Mongolia" Coalition was officially established under a shared vision to eliminate tuberculosis in Mongolia. AC!MN aims to increase meaningful community engagement, promote evidence-based policy, advocacy, and support transparent and sustainable financing.

May 29, 2025



STRATEGY & GOVERNANCE STRENGTHENED

On the second coordinating committee meeting ACT!MN's strategic plan was approved.

July 2-6: Community Action at Playtime

ACT!MN initiated the Healthy Lung pavilion during the biggest music festival in Mongolia, in collaboration with MoH, NCPH, NCCD and MAFMS. We successfully engaged with over 3,000 and enrolled 662 people in CAD X-Ray screening.

March 23-30, 2025



FIRST EVER COMMUNITY DIALOGUE

With ACT!MN and CESI partners, we successfuly organized a 3-part Community Dialogue which included TB survivors, TB fighters, and ACT!MN.

To meaningfuly engage in decision making, four of ACT!MN's members were included in the GC8 working group.

May 22, 2026



COUNTRY DIALOGUE

ACT!MN not only particpated in a country dialogue but actively engaged and played a leading role in the disscusions and overall organization of the event.

Empowering Communities for a Stronger TB Response

Tumendemberel Banzragch, TB Survivor

My name is Tumendemberel, and I am a tuberculosis survivor. In 2023, I was first invited to participate in this project when I received a phone call from Ms. Oyun from the Surveillance and Research Department of the National Center for Communicable Diseases, asking if I would be willing to attend a community TB meeting.

Later in 2023, based on my own interest and motivation, I became a member of the community-led monitoring (CLM) group. Through regular participation in APCASO's capacity-building trainings and meetings, I gained knowledge and a clearer understanding of how community-led monitoring functions, including its roles, responsibilities, and areas of focus.
As a result of my involvement in the project, I had the opportunity in 2025 to participate in a National High-Level Meeting attended by government officials, decision-makers, TB survivors, and media representatives. With the support of the Mongolian Anti-Tuberculosis Coaliion, I represented people affected by TB and shared my personal experience—highlighting the challenges I faced during my illness, including the need for psychosocial support, social protection, financial assistance, nutritional support, and detoxification treatment.

In 2024, I also contributed to discussions during the German-Mongolian Debt Swap Initiative consultations, advocating for funds to be allocated toward essential needs for people affected by TB, such as food support and detoxification treatment. Being able to contribute, even in a small way, to support fellow Mongolians facing similar struggles gave me a strong sense of purpose and positivity.

I believe that sharing my story and participating in these activities has contributed, to some extent, to strengthening the community-led monitoring system and increasing community engagement in Mongolia under the APCASO programme implemented between 2023 and 2026.

The technical support provided by APCASO has been very valuable in helping people affected by TB better understand what "community" and "community participation" mean, how to address and advocate for solutions to the challenges they face, and how to actively engage in TB-related efforts. Through training and information-sharing, the programme has strengthened our capacity and empowered us to take a more active role in addressing TB in Mongolia.



Сүрьеэтэй тэмцэх ажлыг бэхжүүлэхэд олон нийтийг чадавхжуулах нь

Түмэндэмбэрэл

Намайг Түмэндэмбэрэл гэдэг. Би сүрьеэг даван туулагч байна. 2023 онд ХӨСҮТ-ийн Тандалт судалгааны албанаас Оюун гэдэг хүн та сүрьеэгийн олон нийтийн уулзалтад ирж оролцох боломж байна уу? гэж утсаар санал тавьж энэ төсөлд анх ирж оролцсон.

2023 онд өөрийн хүсэл сонирхлоор олон нийтээр удирдуулсан хяналтын гишүүн болсон. APCASO-ийн чадавхжуулах сургалт, уулзалтад тогтмол хамрагдаж, мэдээ мэдээлэл авч, олон нийтээр удирдуулсан хяналт яаж ажиллах, ёстой, ямар ямар чиглэлээр ажиллах ёстой талаар тодорхой хэмжээнд ойлголттой болж суралцсан. Төсөлд оролцсоноор 2025 онд болсон яам, тамгын газар, шийдвэр гаргагчид болон даван туулагч, хэвлэл мэдээлэл хамтарсан Үндэсний дээд хэмжээний уулзалтад Монголын Сүрьеэтэй тэмцэх холбооны дэмжлэгтэйгээр сүрьеэд өртсөн иргэдээ төлөөлөн сүрьеэг даван туулахад ямар ямар бэрхшээл тулгарч, яаж зовж даван туулсан талаараа сэтгэл зүйн тусламж үйлчилгээ, нийгмийн хамгаалал, санхүүгийн дарамт, хүнс хоолны дэмжлэг, хордлого тайлах эмчилгээ зайлшгүй шаардлагатай байсан түүхээ хуваалцсан.

2024 онд болсон Герман Монголын өр хөрвүүлэх хэлэлцүүлэгт тус хөрөнгийг сүрьеэд өртсөн иргэдэд зайлшгүй шаардлагатай байгаа хүнс, хоол, хордлого тайлах эмчилгээнд зарцуулахаар шийдвэр гаргуулахад хувь нэмрээ оруулсан. Энэ үйл явдал хүнд хэцүү өвчнөө даван туулж байгаа зовлон нэгт монголчууддаа бага ч гэсэн өөрийн зүгээс тус хүргэлээ гэж өөртөө маш өөдрөг сэтгэгдэлтэй үлдсэн.

Хуваалцаж байгаа энэ түүх маань 2023-2026 онд хэрэгжиж байгаа APCASO байгууллагын Монголд олон нийтээр удирдуулсан хяналтын тогтолцоог бэхжүүлэх, оролцоог нэмэгдүүлэх үйл ажиллагаанд тодорхой хэмжээнд хувь нэмрээ оруулсан гэж бодож байна.

APCASO-ийн бидэнд үзүүлж буй техникийн тусламж нь манай сүрьеэд өртсөн иргэдэд олон нийт гэж юу вэ? олон нийтийн оролцоо гэж юу вэ? Тулгараад байгаа асуудлуудаа яаж шийдэх вэ? Шийдвэрлүүлэх вэ? яах ёстой талаараа олон нийтээр удирдуулсан хяналтыг чадавхжуулж, мэдээлэлжүүлж цаашид сүрьеэд ямар оролцоотой байх вэ? яаж ажиллах талаар сургалт мэдээллээр хангаж ажилласан.



Providing Accurate Information to Fight TB

Davaajav Khandjav, TB Survivor, MTC

I first participated in a community empowerment training. Following that, I helped organize support group meetings for people affected by tuberculosis. I also joined the ACT.MN coalition and worked as part of a team conducting active TB case finding during the Playtime music festival.

Within the framework of the CE-SI project, many important activities were implemented. Through the “Support Group Meetings for People Affected by Tuberculosis,” we provided accurate information about TB, offered psychological counseling, strengthened confidence in successful treatment outcomes, and facilitated consultations with professional doctors. I am pleased that these efforts contributed, even in a small way, to supporting people affected by TB in their recovery. Many individuals in this group would otherwise not have access to such services.

From my own experience, when I completed a 9-month treatment for multidrug-resistant tuberculosis, I understand how harmful misinformation can be. I personally believed inaccurate information about TB at one point. Therefore, I fully recognize the importance of providing correct information, offering psychosocial support, and demonstrating that TB is curable through real-life examples.

The implementing organization, the Mongolian Anti-Tuberculosis Coalition, provided us with guidance, methodologies, and technical support. They also ensured financial support for organizing support group meetings, including refreshments and transportation costs for participants.

I would like to express my appreciation to the project management and donors for funding these activities, which have contributed to empowering communities affected by TB and supporting patients in their recovery—ultimately helping to save lives.

Furthermore, the establishment and ongoing support of the TB-Free Mongolia coalition, along with continuous capacity-building efforts, are making a significant contribution toward the long-term goal of eliminating tuberculosis in Mongolia.



Үнэн зөв мэдээллээр сүрьеэтэй тэмцэх нь

Даваажав, Х.Даваажав, Сүрьеэг даван туулагч, МСТХ

Анх олон нийтийг чадавхжуулах сургалтад хамрагдаж байсан. Сүрьеэгээр өвдсөн иргэдийн Дэмжих бүлгийн уулзалт зохион байгуулсан. Сүрьеэгүй Монгол эвслийн гишүүнээр нэгдсэн. Playtime хөгжмийн наадамд сүрьеэгийн идэвхтэй илрүүлэг хийх ажлын хэсэгт ажилласан.

“Олон нийтийн оролцоо стратегийн санаачилга” төслийн хүрээнд олон чухал ажил хийгдсэнээс "Сүрьеэгээр өвдсөн хүмүүсийн дэмжих бүлгийн уулзалт"-аар дамжуулан сүрьеэгийн талаар үнэн зөв мэдээлэл өгсөн, сэтгэл зүйн зөвлөгөө өгсөн, эмчилгээний амжилтын талаар итгэл үнэмшил төрүүлсэн, мэргэжлийн эмчээр зөвлөгөө өгсөн гэх мэт үйл ажиллагааг хэрэгжүүлсэн бөгөөд сүрьеэгээр өвдсөн олон нийт маань эдгэхэд бага ч гэсэн хувь нэмрээ оруулсанд баяртай байна. Учир нь хөтөлбөрийн хүрээнд өвдсөн олон нийт маань эдгээр үйлчилгээг авах боломжгүй байдаг.

Миний хувьд ч гэсэн олон эмэнд тэсвэртэй сүрьеэгийн 9 сарын эмчилгээг дуусаж байхад сүрьеэгийн талаар ам дамжсан худал мэдээлэлд итгэж явсан учраас өвдсөн олон нийтэд үнэн зөв мэдээлэл өгөх, сэтгэл зүйн дэмжлэг үзүүлэх, сүрьеэ бүрэн эдгэрдэг гэдгийг бодитоор харуулах ямар чухал болохыг мэддэг.

Төсөл хэрэгжүүлэгч буюу Монголын Сүрьеэтэй тэмцэх Холбооны зүгээс ажиллах арга зүй заавар зөвлөмжөөр хангаж ажилласан. Дэмжих бүлгийн уулзалт хийхэд оролцогчдын цай, кофе, хөнгөн зууш болон унааны мөнгө олгоход санхүүгээр хангаж ажилласан.

Төслийн удирдлага буюу санхүүжүүлэгчийн зүгээс энэхүү арга хэмжээг санхүүжүүлснээр сүрьеэгийн олон нийтийг чадавхжуулж, өвдсөн олон нийтийг эдгэрэхэд хувь нэмрээ оруулж нэг ч гэсэн хүний амь аварсанд талархаж байна.

Мөн Монгол Улсад сүрьеэгүй Монгол эвслийг байгуулж ажиллах арга зүйгээр тогтмол хангаж олон нийтийг чадавхжуулж ажилладаг нь цаашид Монгол Улсад сүрьеэг устгах том үйл хэрэгт ихээр нөлөөлж байна.



Influencing Policies, Changing Lives

Anudari Anar, Youth Lead Mongolia

During the development of the Debt Swap Initiative project, we organized and participated in community consultations, where we listened to and conveyed the needs and priorities of communities. Although opportunities for meaningful participation had been limited in the past—and often remained only as recommendations—I initially had concerns that this might be another similar experience. However, seeing that our inputs were genuinely reflected in the project was very encouraging and rewarding.

Even though we are not a principal recipient, being able to contribute to the well-being of communities—and ultimately to society as a whole—is something we consider both significant and a source of pride.

In addition, within the CE-SI framework, regular—though still limited—engagement between HIV-focused civil society organizations and the comprehensive TB programme implementers created more than just working relationships. It helped build lasting trust, enabling ongoing support and information exchange. I see this as a foundation for stronger, strategic collaboration moving forward.

One of the most meaningful changes during the project implementation was the opportunity to engage with government institutions. We established collaboration with the HIV/STI Surveillance and Research Unit of the National Center for Communicable Diseases, which allowed us to participate in meetings and present research findings. Through this collaboration and information exchange, we began providing psychosocial support and referral services for people living with HIV.

We focused on supporting newly diagnosed individuals by helping them understand that it is possible to live a healthy life, assisting them with disclosure to their families when appropriate, and guiding them to better understand and manage potential risks. We also connected them with professional psychologists and enabled access to free counseling services, which has clearly contributed to improving their quality of life.

This experience gave me an important realization: true impact is not only seen in policies or projects, but in real changes in people's lives.

Looking ahead, we aim to further strengthen and sustain these services, with the goal of creating a more self-sustaining system where individuals can access comprehensive and integrated health services. This represents a significant step forward.



Бодлогод нөлөөлж, амьдралыг өөрчлөх нь

А.Анударь, Залуу эрсдэлт бүлгийн манлайлал

Өр хөрвүүлэх санаачилгын төслийг боловсруулах явцад олон нийтийн хэлэлцүүлгүүдийг зохион байгуулж мөн оролцож олон нийтийн хэрэгцээ шаардлагыг сонсон бас дамжуулж оролцсон. Олон жилийн хугацаанд бодитойгоор оролцох орон зай цөөхөн тохиолдсон ч зөвхөн зөвлөмж болж үлддэг тул мөн л тийм айдастай байсан ч саналууд бодитойгоор тусгагдсан нь маш их баяр төрүүлсэн.

Хэдий салбар хүлээн авагч (Глобал сангийн) биш ч гэсэн олон нийтийн цаашлаад бүх нийтийн сайн сайхан байдалд нөлөө үзүүлж чадаж байх нь бидний хувьд хамгийн том бөгөөд бахархууштай.

Үүнээс гадна CE SI-н хүрээнд ХДХВ-ийн салбар хүлээн авагч төрийн бус байгууллагууд болон сүрьеэтэй тэмцэж буй эрүүл мэндийн цогц хүлээн авагч хооронд цөөхөн ч гэсэн тогтмол уулзах нь зөвхөн ажлын холбоо биш цаашид ч бат суугдсан харилцан итгэлцэл болж дэмжлэг мэдээлэл солилцох боломж бүрдсэн, энэ нь улам илүү услагдаж өгсөн стратегийн хамтралын гүүр болсон гэж харж байна.

Хамгийн утга учиртай өөрчлөлтүүдийн нэг нь төслийн хэрэгжилтийн явцад төрийн байгууллагуудтай холбогдож эхэлсэн бөгөөд ХӨСҮТ-ийн ХДХВ, БЗДХ-ын тандалт судалгааны албатай хамтын ажиллагаа үүсэж, хуралдах мөн судалгааны үр дүнгээ таниулах боломж олдсон. Энэ хамтарлаар хоорондоо мэдээлэл солилцсоны үр дүнд ХДХВ-тэй хүмүүст чиглэсэн нийгэм сэтгэл зүйн дэмжлэг үзүүлж холбон зуучилж эхэлсэн.

Шинээр ХДХВ илэрсэн, оношоо сонссон хүнд эрүүл амьдрах боломжтойг ойлгуулан гэр бүлд нь come out хийх, шаардлагагүй эрсдэлтэй тохиолдолд зөвөөр ойлгуулах зэрэг дэмжлэг өгөхөд анхаарсан. Мөн мэргэшсэн сэтгэл зүйчидтэй холбон өгч, зөвлөгөөг үнэ төлбөргүй авах боломж олгосон нь хүний сайн сайхан амьдралын чанарт үнэхээр дэмжлэг болж байгааг харах байлаа.

Энэ нь нэг чухал мэдрэмж надад өгсөн нь бодлого төсөл дээр биш бодит хүний амьдралд өөрчлөлт харахад жинхэнэ үр дүнд хүрдэг юм байна.

Ирээдүйд энэ үйлчилгээг илүү тогтворжуулан өөрийгөө тэтгэх боломжтой эрүүл мэндийн үйлчилгээг цогц авах боломжтой болох зорилго тавин ажиллаж байгаа нь маш том алхам билээ.




NEPAL

Journey of Community Voice, Leadership, and Impact

From TB Survivor Support Groups to a National Community-led Movement

2021



PHASE 1: FORMATION OF TB SURVIVOR SUPPORT GROUP

Mobilisation and identification of TB survivor groups across Nepal. Concept of TB survivor engagement introduced in Nepal.

March 2: Letter to CCM
Formal letter submitted to advocate for TB constituency within CCM Nepal.

2021 to 2022

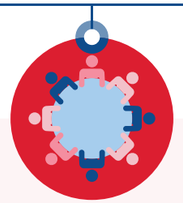


CAPACITY BUILDING AND MOBILISATION

Series of capacity building workshops and orientations conducted for TB survivors across different parts of Nepal.

April 2022: TB Constituency in CCM Nepal
TB constituency successfully selected its representative to CCM Nepal, legitimised and acknowledged within a short period of around 2 years.

2023



COMMUNITY, RIGHTS, AND GENDER ASSESSMENT

Trishuli Plus, in collaboration with Stop TB Partnership, Global Fund, Save the Children International, and APCASO, led the CRG Assessment of TB for the first time in Nepal. The action plan from the assessment is being implemented.

2024



PHASE 2 BEGINS: THE ORGANISATION MOVES AHEAD

ACT Nepal Interim Committee Formed:
Series of mobilisations and consultations to identify TB survivor groups.

ACT Nepal Interim Committee established.

April:
National community engagement plan developed.

Blue Diamond Society joined as HIV partner.

Focus on stronger engagement of TB communities across Nepal.

2025



ACT NEPAL FORMALLY ESTABLISHED

June: ACT Nepal formally established
National network of TB survivors and affected communities officially formed

Steering Committee established:
An inclusive process led to the formation of ACT Nepal Steering Committee, which strengthened governance, representation, and leadership.

November: Participation in TB NSP Consultation
ACT Nepal members participated in the National TB Strategic Plan (NSP) consultation.

2026



NATIONAL CONSULTATION FOR GC8

The national consultation for Global Fund Grant Cycle 8 (GC8) was conducted in collaboration with NTCC and CCM Nepal.

ACT Nepal representatives contributed community perspectives and priorities.

Rising with Courage and Hope

Rajiv Kumar Sharma

My name is Ranjiv Kumar Sharma. I am a youth representative for ACT Nepal. I come from Sarlahi district in Madhesh Province.

I was studying in class 10. Initially, I was very cheerful and energetic. I used to play with my friends and sing songs at school. But gradually, my body became weaker. I started having a continuous cough. At night, I would get a fever and sweat. My mother used to ask me, “Son, why do you look so thin and dried up?” I would laugh it off and say, “It’s nothing, Mother; it must just be a cold.” But it was no ordinary cold. Day by day, my coughing increased. Sometimes, blood-mixed sputum also started coming out. People in the village began to gossip. They would whisper about what kind of disease I had contracted and whether it might spread to others. I was forced to stop going to school. My friends also started keeping their distance. I began sitting alone in a corner of the house. My heart was filled with fear and pain. I thought to myself, my dreams are over now.

One day, my father took me to the hospital at the district headquarters. After many tests, the doctor said, “You have tuberculosis (TB). But there is no need to be afraid; if you take your medicine regularly, you will be cured.”

As soon as I heard the word TB, my heart trembled. In the village, TB was considered a major and terrifying disease.Some people didn’t even think a person could survive after contracting such a disease. Now, I started taking medicine regularly for up to 6 months. Due to the side effects of the medicine, I sometimes felt nauseous and my head ached. But my mother’s encouragement never waned. My father used to tell me, “You are strong. You will definitely get cured.” From time to time, I went to collect my medicine. I had to go far to get the medicine.

Slowly and gradually, time passed by. I started recovering gradually. My cough decreased, and strength returned to my body. However, TB had already changed my life. I started going to school again. But I could never mingle with others like before. Because it had been many days since I last attended school regularly.

One day, a phone call came from the health post saying that I needed to participate in a program. In that program, I became acquainted with the members of ACT!Nepal. At that time, I couldn’t speak at all. After ACT!Nepal provided various types of training, I started participating actively.

They invited me for the first time to participate in a program. After participating in the program, I used to find it difficult to speak as well. Listening to the stories of others made me feel very better. TB is not a major issue at all. After learning about all these things, I finally understood what ACT Nepal, CCM, and the Global Fund are.

After ACT Nepal conducted these kinds of programs, I was able to spread information and public awareness to individuals affected by Tb and within society and the community. After a few days, and now currently, I go door-to-door and educate people that having TB is not a matter of shame. If treated in time, it gets cured. Fear and the wrong mindset of society are bigger than the disease itself. The children of the village respect me now. My life taught the village a big lesson—disease can make a person weak, but courage and hope teach you how to rise again. My story is important for individuals affected by tuberculosis in our community, villages, and across Nepal.



राजिव कुमार शर्माको कथा

मेरो नाम राजिव कुमार शर्मा हो। म ACT Nepal मा युवा प्रतिनिधिको रूपमा छु। म मधेस प्रदेश सर्लाही जिल्लाबाट प्रतिनिधित्व गर्दछु।

सुरुवाती दिनहरुमा म निकै हाँसिखेल्ने र फुर्तिलो थिएँ। साथीहरूसँग खेल्थेँ, विद्यालयमा गीत सुनाउँथेँ। जब म कक्षा १० मा पढ्थेँ, बिस्तारै मलाई मेरो शरीर कमजोर हुँदै गएको अनुभुति हुन थाल्यो। लगातार खोकी लाग्न थाल्यो। राति ज्वरो आउथ्यो, पसिना बग्थ्यो। आमाले सोध्नुहुन्थ्यो "बाबु, किन यति सुकेको जस्तो देखिन्छस् हँ?" म हाँसेर भन्थेँ "केही होइन आमा, चिसो लागेको होला।" तर त्यो साधारण चिसो थिएन। दिनप्रतिदिन मेरो खोकी बढ्दै गयो। कहिलेकाहीँ रगत मिसिएको खकार र थुक पनि निस्किन थाल्यो।

गाउँमा मानिसहरुले कुरा काट्न थाले। मलाई कस्तो रोग लागेको छ र कतै सर्छ कि भनेर कुरा काट्दै थिए। म विद्यालय जान छोड्न बाध्य भएँ। साथीहरू पनि टाढिन थाले। म घरको कुनामा एक्लै बस्न थालेँ। मेरो मनभित्र डर र पीडा भरिएको थियो। मैले सोचेँ कि मेरो सपना अब सकियो। एक दिन बाबुले मलाई सदरमुकामको अस्पताल लानुभयो। धेरै परीक्षणपछि डाक्टरले भने "तिमीलाई क्षयरोग लागेको छ, तर डराउनुपर्दैन, नियमित औषधि खाए निको हुन्छ।" क्षयरोग भन्ने शब्द सुनासाथ मेरो मन काँप्यो। गाउँमा क्षयरोग लाई ठुलो र डरलाग्दो रोग मानिन्थ्यो। कतिपयले त यस्तो रोग लागेपछि मानिस बाँच्छ र भनेर पनि सोध्थे रे! अब म ६ महिना सम्म नियमित औषधि खान थालेँ। औषधिको असरले कहिलेकाहीँ मलाई वाकवाकी लाग्थ्यो, टाउको दुख्थ्यो तर आमाको हौसलामा कहिल्यै कमी भएन। बुबाले भन्नुहुन्थ्यो कि तिमी बलियो छौ, तिमी अवश्य निको हुनेछौ। मैले नियमित औषधि सेवन गर्न थालेँ। औषधि लिन टाढा जानु पर्थ्यो। बिस्तारै-बिस्तारै समय बित्दै गयो। म बिस्तारै निको हुन थालेँ। खोकी कम भयो, शरीरमा शक्ति जाग्यो। तर क्षयरोगले मेरो जीवन बदलिसकेको थियो। मैले फेरि विद्यालय जान थालेँ। तर पुरानो जस्तो सहजता कहिल्यै हुन सकेन। विद्यालय जाँदा जाँदै धेरै दिन भयो।

एक दिन स्वास्थ्य चौकीबाट एउटा कार्यक्रममा सहभागी हुनको लागि फोन आयो। त्यो कार्यक्रममा मैले ACT Nepal का सदस्यहरू सँग परिचित भएका थिएँ। त्यति बेला म केही पनि बोल्न सक्दैनथेँ। ACT Nepal ले विभिन्न प ्रकारका तालिम दिइसकेपछि म सक्रिय रूपमा सहभागी हुन थालेँ। ACT Nepal ले प्रथम पटक कार्यक्रममा सहभागी हुनका लागि आमन्त्रण गर्नुभयो। कार्यक्रममा सहभागी भएपछि मलाई बोल्न सहज हुनथाल्यो। सदस्यहरूका कुरा सुनेर मलाई धेरै राम्रो लाग्यो। क्षयरोग कुनै पनि ठुलो कुरा होइन। मलाई यस्ता-यस्ता कुरा थाहा पाएपछि बल थाहा पाएँ।

ACT Nepal, CCM र Global Fund बारे थाहा पाएँ। ACT Nepal को यस्ता कार्यक्रममा सहभागी भएपछि मलाई बल्ल थाहा भयो कि ACT Nepal सँग जोडिएको यस्ता यस्ता संस्था छन् भनेर। अहिले क्षयरोग प्रभावित व्यक्तिलाई र समाज समुदायमा पनि जानकारी र जनचेतना फैलाउन सकेको छु।

अब अहिले म घरघरमा गएर मानिसलाई क्षयरोगको बारेमा भन्ने गरेको छु। क्षयरोग लाग्नु केही नराम्रो कुरा होइन। समयसमयमा उपचार गरे निको हुन्छ। रोग भन्दा डर र समाजको गलत सोच ठुलो छ। गाउँका बालबालिकाले अहिले मलाई सम्मान गर्छन्। मेरो जीवनको एउटा मार्गनिर्देशनले मलाई एउटा ठुलो पाठ सिकायो, रोगले मानिसलाई कमजोर बनाउन सक्छ तर हिम्मत र आशाले फेरि उठ्न सिकाउँछ। यो कथा हाम्रो समुदाय, गाउँ र नेपालमा भएको क्षयरोग प ्रभावित व्यक्तिका लागि पनि महत्त्वपूर्ण छ।



Overcoming TB with Information, Care and Treatment

Archana Kumari Sah

My name is Archana Kumari Sah. I am a member of ACT! Nepal. I am from Madhesh Province (JNK / Janakpur). I was 16 years old when I got TB. I had just given my SEE (Secondary Education Examination) result. Suddenly one day, I got fever. As this continued, after about a week, I started getting a fever specifically during the evenings. I also faced issues like chest wheezing while breathing. Following this, we went to see a doctor who is a family member, and they prescribed some medications. However, that medicine only cured the fever. The underlying symptoms remained. Consequently, I stayed sick at home for about a month. After that, we went to a government hospital where they advised an X-ray. After doing the X-ray, the doctors confirmed that it was TB. Because it was around the Dashain and Tihar festival season, they didn't give the medicine right away. Only after talking to a person from the laboratory did they agree to dispense the medication. Furthermore, because the medicine was very strong, I was also forced to take medication for gastric issues. The health worker advised and suggested that I must take the medicine for about six months.

Since I was a college student, it was very difficult for me to take the medication. After my classes finished, I always had to go to the health post to collect the medicine. Because the medicine was very strong, I had to face side effects in the form of pimple-like skin issues on my face. After taking the medicine, my weight also started to increase. Amidst all this, I did a follow-up test after two months. The report came back good. It was during this period that I met with the members of Trishuli Plus. At that time, after we learned a little bit more about TB, I was able to understand it better. After that, once my TB was cured, Trishuli Plus invited me to participate in a program for the first time.

After Trishuli Plus educated us about TB, I no longer felt that TB was a major, terrifying disease. We came to understand that a person diagnosed with TB can recover well if given the proper medicine, nutritious food, and good care. In the second program, we were invited to be part of ACT! Nepal. In this, individuals from various provinces were made members. In the third program, as members from different provinces, we formulated plans on how to work within our respective areas. After learning about these aspects through ACT! Nepal, I also started speaking out and opening up to everyone that TB is not a major disease; no disease is inherently too big to overcome. It simply requires proper care and necessary medication according to the illness. If we follow this, we won't have to fear any disease. A disease that lasts six months or a year is not a major illness—if treated properly, it can be cured quickly.



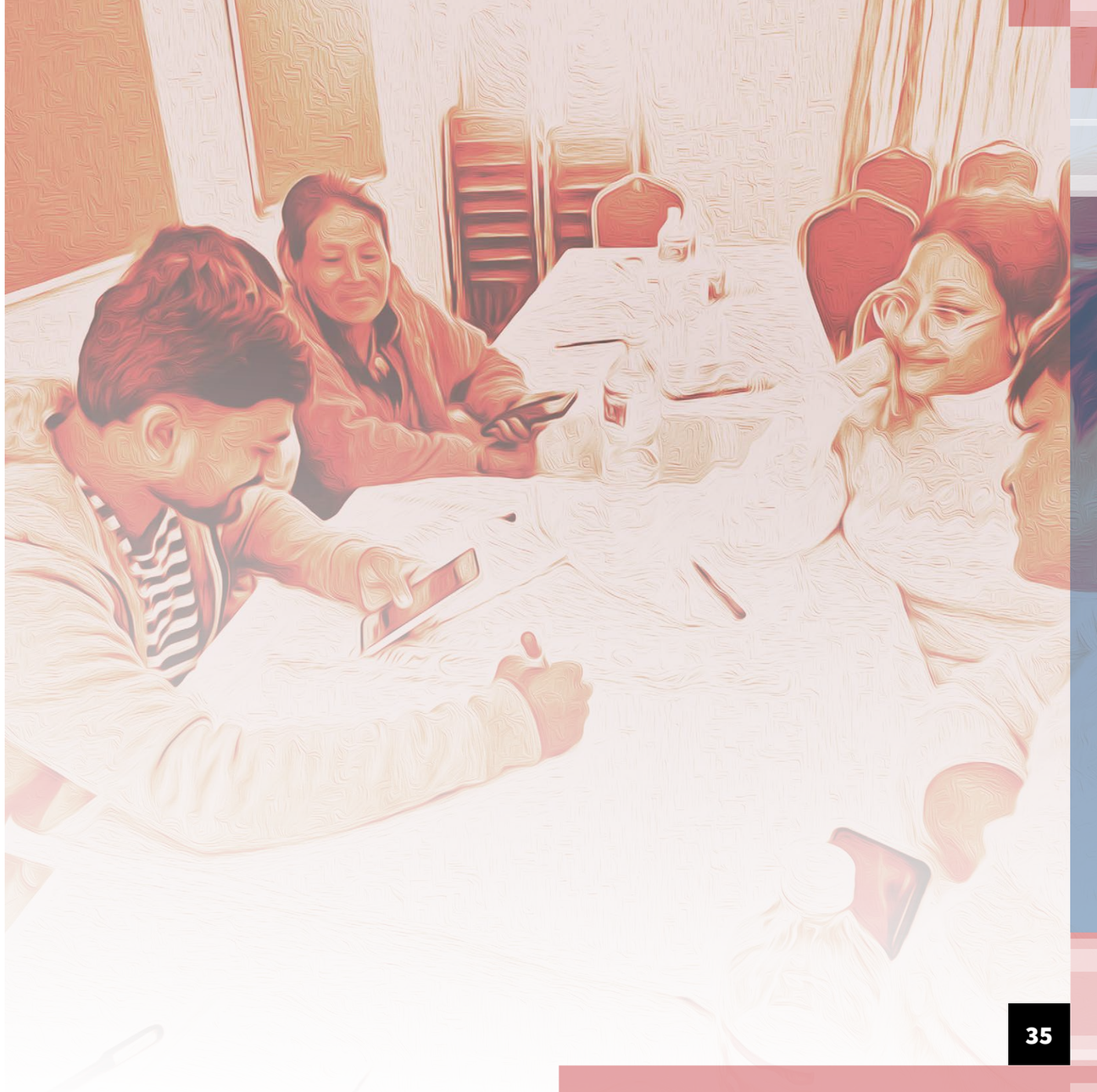
अर्चना कुमारी साहको कथा

मेरो नाम अर्चना कुमारी साह हो । म पनि ACT Nepal को एक सदस्य हुँ। म मधेस प्रदेश जनकपुरबाट प्रतिनिधित्व गर्दछु। जब म १६ वर्षको थिएँ, मलाई जब क्षयरोग (TB) भएको थियो । मैले भर्खरै एस.ई.ई. (SEE) को परिक्षा दिएकी थिएँ। अचानक एक दिन मलाई ज्वरो आयो। यो क्रम चल्दै जाँदा १ हप्ता जति मलाई बेलुका-बेलुका मात्र ज्वरो आउने गर्थ्यो। मलाई श्वास फेर्न पनि समस्या हुन्थ्यो, छाती घ्यारघ्यार हुने जस्ता समस्या हुन्थ्यो । त्यसपछि हामी एउटा डाक्टर; जो हाम्रो नाता पर्नुहुन्थ्यो उहाँकहाँ गयौँ र उहाँले केही औषधि दिनुभयो। त्यो औषधिले ज्वरो मात्र ठीक हुन्थ्यो तर भित्रको रोग ठीक भएन। त्यसपछि म १ महिना सम्म घरमै बिरामी भएर बसेँ। त्यसपछि हामी सरकारी अस्पताल गयौँ र त्यहाँ डाक्टरले एक्सरे (X-ray) गर्न भन्नुभयो। एक्सरे (X-ray) गरेपछि डाक्टरले क्षयरोग हो भनेर प्रष्ट पार्नुभयो। दशैँ र तिहारको समय भएकाले सरकारी अस्पतालले औषधि तुरुन्तै दिएन। एउटा ल्याबको मान्छेसँग कुरा गरेपछि मात्र औषधि दिन तयार भए। औषधि धेरै भएकाले ग्यास्ट्रिकको औषधि पनि खान बाध्य भएँ। स्वास्थ्यकर्मीले मलाई ६ महिना सम्म औषधि खानुपर्छ भनेर सल्लाह सुझाव दिनुभयो।

म कलेज पढ्ने विद्यार्थी भएकाले मलाई औषधि खान धेरै गाह्रो हुन्थ्यो। मेरो कलेज सकिएपछि म सधैँ स्वास्थ्य चौकीमा औषधि लिन जानु पर्थ्यो। औषधि धेरै कडा भएकाले अनुहारमा बिमिरा जस्ता समस्याहरूको सामना गर्नुपर्यो। औषधि खाएपछि मेरो तौल पनि बढ्न थाल्यो। यसै बीचमा मैले २ महिनापछि फलोअप जाँच गराएँ। रिपोर्ट राम्रो आयो। यही अवधिमा मेरो लिशूली प्लसका सदस्यहरूसँग भेट भयो।

त्यो समयमा हामीलाई क्षयरोगको बारेमा अलिअलि थाहा पाएपछि मैले त्यसबारे बुझ्न सकेँ। त्यसपछि क्षयरोग निको भएपछि प्रथम पटक कार्यक्रममा सहभागी हुनका लागि लिशूली प्लसले बोलाउनुभयो। लिशूली प्लसले हामीलाई क्षयरोगको बारेमा भनेपछि मलाई क्षयरोग ठुलो रोग हो भन्ने लागेन। क्षयरोग प्रभावित भएको व्यक्तिलाई औषधि, पौष्टिक तत्व र राम्रोसँग हेरचाह गरेमा निको हुन सक्छ भन्ने कुरा मलाई थाहा भयो। दोस्रो पटक मलाई ACT Nepal बाट कार्यक्रममा सहभागी हुन बोलाईयो। यस कार्यक्रममा देशका विभिन्न प्रदेशका क्षयरोग संक्रमित तथा प्रभावित व्यक्तिहरूलाई विभिन्न प्रदेश सदस्यको जिम्मेवारी दिएका थियौँ ।

तेस्रो कार्यक्रममा हामी विभिन्न प्रदेशको सदस्य भएकाले आफ्ना क्षेत्रहरूमा कसरी काम गर्ने भन्ने योजनाहरू बनाएका थियौँ। ACT Nepal मा यस्ता कुराहरू थाहा पाएपछि म पनि सबैसँग खुलेर कुरा गर्न थालेँ। क्षयरोग कुनै ठुलो रोग होइन, कुनै पनि रोग ठुलो हुँदैन। त्यसलाई राम्रोसँग रूपरेखा अनुसार र औषधिको आवश्यकता हुन्छ। यदि यस्तो गरियो भने हामी कुनै पनि रोगसित डराउन सक्दैनौँ। ६ महिना र ९ महिनाको रोग ठुलो रोग हुँदैन, राम्रोसँग उपचार गर्यौँ भने छिट्टै निको हुन सक्छ। अब अहिले म घरघरमा गएर मानिसहरूलाई यही सन्देश भनिरहेको छु। क्षयरोग लाग्नु कुनै नराम्रो कुरा होइन। समयमै उपचार गरे यो रोग निको हुन्छ। रोग भन्दा डर र समाजको गलत सोच ठुलो छ। गाउँका बालबालिकाहरूले अहिले मलाई सम्मान गर्छन्। मेरो जीवनले मलाई एउटा ठुलो पाठ सिकायो; रोगले मानिसलाई कमजोर बनाउन सक्छ तर हिम्मत र आशाले फेरि उठ्न सिकाउँछ। यो कथा हाम्रो समुदाय, गाउँ र नेपालमा भएका क्षयरोग प्रभावित व्यक्तिहरूका लागि पनि महत्त्वपूर्ण छ



Shaping Policies Through Survivors' Voices

Deepak Shrestha

My name is Deepak Shrestha and I am HIV positive and a TB survivor. I have been involved in Trishuli Plus for long time and worked in with TP for 2 years as community mobiliser. When ACT Nepal was formulated, I was the interim president as I was also a TB survivor.

After the formulation, we have visited many TB survivors. I took sessions about TB and after taking the session for a week, I came to know many things that I didn't know about TB. After that I had the chance to go Mongolia for cross-country learning programme through the project and was also when ACT!Mongolia was officially launched.

In Mongolia, people from different organizations came together to let us know about the condition of TB cases in there. People and activists in Mongolia were very good and selfless. And I also got the chance to meet people from ACT! Pakistan and their work motivated me to work more wholeheartedly. After coming back from Mongolia, we officially established ACT! Nepal as an organization and I became an official member.

Later, I also had the opportunity to visit Jakarta, Indonesia for another cross country learning experience, where I learned about community engagement and advocacy through projects like COOPER, also implemented by ACT!AP and APCASO . After returning to Nepal, we were invited to participate in discussions related to National Strategic Planning (NSP) process by the National Tuberculosis Control Centre (NTCC). For the first time, I realize that survivors' voices truly matter in shaping national policies and programs.



दीपक श्रेष्ठको कथा

मेरो नाम दीपक श्रेष्ठ हो। म एच.आई.भी. संक्रमित र क्षयरोग (TB) बाट निको भएको व्यक्ति (survivor) हुँ। म लामो समयदेखि त्रिशूली प्लसमा आबद्ध छु र मैले त्यहाँ २ वर्षसम्म एच.आई.भी. संक्रमित र क्षयरोग निदान तथा उपचार कार्यक्रममा सामुदायिक परिचालक (community mobilizer) को रूपमा काम गरेँ। जब नेपालमा क्षयरोग संक्रमित तथा प्रभावित व्यक्तिहरुको उपचारमा पहुँच तथा पैरवीको लागि 'एक्ट नेपाल' (ACT Nepal) को गठन भयो, म यसको अन्तरिम अध्यक्ष बनेँ, किनभने म आफैँ पनि क्षयरोग निको भएको व्यक्ति थिएँ।

'एक्ट नेपाल' गठन भइसकेपछि हामीले क्षयरोग उपचाररत तथा निको भएका धेरै व्यक्तिहरूलाई भेट्यौँ। मैले क्षयरोगको बारेमा (यसका सम्पूर्ण पक्ष समेटेर) एउटा सेसन (कक्षा) लिएँ। एक हप्तासम्म सेसन लिएपछि मैले क्षयरोगको बारेमा धेरै नयाँ कुराहरू थाहा पाएँ, जुन मलाई पहिले थाहा थिएन। त्यसपछि म सांस्कृतिक आदानप्रदान (Cultural Exchange) कार्यक्रमका लागि मंगोलिया गएँ, जहाँ 'एक्ट मंगोलिया' (ACT Mongolia) को पनि आधिकारिक रूपमा स्थापना भएको रहेछ। मंगोलियामा विभिन्न संस्थाका मानिसहरू मंगोलियाको क्षयरोगको अवस्थाबारे हामीलाई जानकारी गराउन सँगै आएका थिए। मंगोलियाका मानिसहरू र अभियन्ताहरू (activists) पनि नेपालका जस्तै एकदमै राम्रा र निस्वार्थ भावनाले सेवारत रहेछन्। मैले त्यहाँ 'एक्ट पाकिस्तान' (ACT PK) का मानिसहरूलाई पनि भेट्ने मौका पाएँ, जसको कामले मलाई अझ बढी मनैदेखि काम गर्न प्रेरित गर्यो। मंगोलियाबाट फर्केपछि हामीले आधिकारिक रूपमा 'एक्ट नेपाल' लाई एउटा खुकुलो संस्था (loose organization) को रूपमा स्थापना गर्यौँ र म 'एक्ट नेपाल' को आधिकारिक अध्यक्ष बनेँ।

त्यसपछि मैले अर्को एउटा आदानप्रदान कार्यक्रमका लागि जकार्ता, इन्डोनेसिया जाने अवसर पनि पाएँ, जहाँ मैले 'कपर' (COPPER) जस्ता संस्थाहरू मार्फत सामुदायिक संलग्नता (community engagement) र पैरवी (advocacy) को बारेमा सिक्ने मौका पाएँ। नेपाल फर्केपछि 'एक्ट नेपाल' लाई पहिलो पटक राष्ट्रिय क्षयरोग नियन्त्रण केन्द्र (NTCC) द्वारा राष्ट्रिय रणनीतिक योजना प्रक्रिया सम्बन्धी छलफलहरूमा अर्थपुर्ण सहभागिता गराईयो। राष्ट्रिय नीति र कार्यक्रमहरूलाई सही आकार दिन क्षयरोग निको भएका व्यक्तिहरूको आवाज साच्चै नै महत्त्वपूर्ण हुन्छ भन्ने कुरा मैले महसुस गरेँ। यो सम्पूर्ण यात्राभरि एकजना व्यक्ति जो निरन्तर मेरो साथमा उभिनुभयो, उहाँ करिश्मा बन्जारा हुनुहुन्छ। उहाँको सहयोग, प्रोत्साहन र मप्रतिको विश्वासले मलाई अगाडि बढ्न महत गर्यो।

कुनै समय समुदायबाट हुने लाञ्छना र भेदभावको डर र लाजका कारण म चुपचाप बस्ने गर्थेँ। तर अहिले मलाई थाहा छ कि यदि हामी जस्ता रोगबाट निको भएका व्यक्तिहरू अगाडि बढेर बोलेनौँ भने धेरै महत्त्वपूर्ण कथाहरू कतै नसुनिनेगरि हराउनेछन्। मेरो यात्राले मलाई सिकाएको छ कि पीडा पनि एउटा उद्देश्य बन्न सक्छ र रोगबाट निको भएका व्यक्तिहरू भोलिका नेता बन्न सक्छन्




PAKISTAN

Journey of Community Voice, Leadership, and Impact

A Voice for Change Advocating for TB Survivors Nationwide

2022



ESTABLISHMENT OF FIVE TB CSGs

Training on their roles and responsibilities was conducted in their respective cities:

TB CSG at Abbottabad	-	24th January
TB CSG at Mardan	-	7th January
TB CSG at Swat	-	3rd February
TB CSG at Kohat	-	17th February
TB CSG at Charsadda	-	16th March

March 21 - 22: Training Conducted in Lahore
Two-day training of selected 30 members of TB CSGs on leadership and advocacy skills.

June 6: Training Conducted in Lahore
One-day training of selected CSGs members on Right to Breathe.

2024



ESTABLISHMENT AND LAUNCHING OF ACT!PK

March 21:
The organisation was officially launched during a national gathering in Islamabad.

May to June: Development of Bylaws and Manual of Operations
This activity was done through a consultant.

July 26 - 27: Training Conducted in Lahore
Training of 30 CSG members on Global Fund — its structure, role, mechanism, and processes.

December: Establishment of SC-ACT!PK
ACT!PK's steering committee was formed.

2025



May: Training of SC-ACT!PK
Training of bylaws and the manual of operations.

July: Training Module Created
Development of the training module on organizational management was done through a consultant.

Reprioritization Consultation
A national-level community and civil society reprioritization consultation was conducted in Islamabad.

Community Engagement
Engagement of SC-ACT! PK with the community and CS CCM members in Islamabad.

October: Mid-term Assessment
This activity was conducted through a consultant.

December: Steering Committee Training
Training of SC-ACT!PK on organizational development.

2026



May: Consultation Workshop
A national-level community and civil society consultation workshop on GC8 was conducted in Islamabad.

Providing Spaces, Making People Visible

Mussarat Jabeen

My name is Mussarat Jabeen. I am from Islamabad, Pakistan. I am a TB survivor. There was a time when my world felt very small. I was not just living with a health condition, I was living with fear. I slowly withdrew from people around me. Even my children stayed at a distance because I was afraid of harming them. I felt alone, even when people were around me.

Then slowly, something began to change. I was connected with the Association of People Living with HIV (APLHIV), and later I joined activities with the Activists Coalition on TB in Pakistan (ACT! PK). For the first time, I felt I was not the only one carrying this experience. That gave me strength I did not know I still had.

In March 2024, I became part of the Community Engagement Strategic Initiative (CE SI). This initiative, funded by APCASO and implemented through ACT! PK in coordination with APLHIV, brought people like me into a space where our voices actually mattered. Not as patients, but as people with experiences that could guide change.

At first, I was very quiet. I did not speak much. I was still learning to trust my voice again. I remember one young boy who used to sit silently in our sessions. He would not look up, and he would not speak. It felt like he had closed himself off from the world. But over time, I saw him change. One day he answered a question. Then he smiled. That small smile stayed with me. It made me realize how powerful it is when someone feels safe enough to be heard.

As I continued, I also changed. I joined trainings on the Global Fund, human rights, TB awareness, and advocacy. Slowly, I stopped only listening and started speaking. I started speaking not just for myself, but for others who were still silent.

What changed most for me was how I see TB now. It is no longer just something medical. It is something that affects dignity, confidence, and how a person sees themselves. I saw this clearly in another woman during a session. She used to sit quietly in the corner. She never spoke. One day, she finally spoke about her rights. Her voice was shaky at first, but she kept going. And as she spoke, something in her changed. She looked stronger. She looked free.

And then I understood something that stayed with me. That woman I was describing… was me.
I had been sitting in that same silence. I had been afraid to speak, afraid to be seen, afraid that my story had ended. But it had not. It was only beginning again in a different way.

Today, I continue to work with communities affected by TB. When people face challenges like medicine shortages or access to care, they now try to speak up and seek help. There is still struggle, but there is also courage.

We started as a few voices. Now we are slowly becoming a collective one. Through CE SI, with the support of APLHIV, ACT! PK, and APCASO, I learned how powerful it is when lived experience is not ignored, but included.

ACT! PK is not just an organization to me. It feels like a space where people are no longer invisible. My journey is still going on. But it no longer feels like silence.

It feels like a voice.

My story matters.

My voice matters.

Our voices matter.



مسرت جبین - ٹی بی پر فتح پانے والی ایک ہمت مند خاتون

اسلام آباد، پاکستان

میرا نام مسرت جبین ہے اور میرا تعلق اسلام آباد سے ہے۔ میں ٹی بی کو شکست دے کر ایک نئی اور بھر پور زندگی گزارنے والی خاتون ہوں۔ میری زندگی میں ایک ایسا دور بھی گزرا جب اس چیلنج نے میری دنیا کو بہت محدود کر دیا تھا. وہ صرف ایک طبی مرحلہ نہیں تھا، بلکہ ایک ایسا وقت تھا جب میں نے غیر یقینی صورتحال کی وجہ سے خود کو اپنوں سے دور کر لیا تھا۔ یہاں تک کہ مامتا کی تڑپ کے باوجود میں نے اپنے بچوں سے بھی فاصلہ رکھا تاکہ وہ محفوظ رہیں۔ اس دوران میں نے خود کو بہت تنہا محسوس کیا۔

مارچ 2024 میں میری زندگی میں ایک نیا موڑ آیا جب میرا رابطہ APLHIV سے ہوا اور بعد ازاں میں نے ACT PK کے ساتھ مل کر کام کرنا شروع کیا۔ وہاں مجھے پہلی بار یہ احساس ہوا کہ میں اس سفر میں تنہا نہیں ہوں اور اس ساتھ نے میرے اندر وہ ہمت پیدا کی جو شاید کہیں اندر چھپی ہوئی تھی۔ یہ اقدام، جسے APCASO نے مالی تعاون فراہم کیا اور ACT PK کے اشتراک سے APLHIV کے ذریعے نافذ کیا گیا، مجھ جیسے لوگوں کو ایک ایسی جگہ پر لے آیا جہاں ہماری آواز کی واقعی اہمیت تھی۔ مریضوں کے طور پر نہیں، بلکہ ان تجربات کے حامل افراد کے طور پر جو تبدیلی کی راہ دکھا سکتے ہیں۔

اس سفر کے دوران میں نے انسانی حقوق، آگاہی اور وکالت (Advocacy) کے حوالے سے بہت کچھ سیکھا۔ اب میں صرف ایک خاموش تماشائی نہیں تھی، بلکہ میں نے ان لوگوں کے لیے آواز اٹھانا شروع کی جو ابھی اس راستے پر نئے تھے۔ میرے لیے یہ اب صرف صحت کا معاملہ نہیں رہا، بلکہ یہ انسان کے وقار اور خود اعتمادی کی بحالی کا مشن بن گیا۔

مجھے یاد ہے ایک خاتون جو بہت جھجک اور شرم محسوس کرتی تھی، لیکن جب اس نے حقوق کی بات کی تو ایک مضبوط اور با اختیار انسان نظر آنے لگی۔ تب مجھے احساس ہوا کہ وہ عورت دراصل میں ہی تھی۔ میں جو خاموش رہنے پر مجبور تھی، اب ایک نئے عزم کے ساتھ آگے بڑھ رہی تھی۔

آج میں اپنی کمیونٹی کے ساتھ مل کر کام کرتی ہوں۔ اب اگر کہیں کوئی رکاوٹ یا مشکل آئے، تو لوگ خاموش نہیں بیٹھتے بلکہ مل کر اس کا حل تلاش کرتے ہیں۔ ہم نے چند آوازوں سے سفر شروع کیا تھا...



Ending Stigma and Restoring Hope

Robina

My journey with TB was painful, emotional, and life changing. In 2007, my husband became seriously ill. After several medical tests, we learned that he was living with HIV and had also developed Tuberculosis (TB). Those were extremely difficult days for our family.

Before his TB treatment could properly begin, he faced discrimination because of both HIV and TB. Due to stigma and lack of support, his treatment could not be completed, and eventually, I lost him. At that time, I did not have enough information or understanding about these health conditions, but that tragedy left a deep fear in my heart. I often wondered if things could have been different if timely treatment and support had been available.

Years later, my own health also started deteriorating. My mother encouraged me to get tested, and I learned that I was HIV positive. Hearing this brought back memories of my husband's suffering, and I became overwhelmed with fear and uncertainty about my future.

During that difficult period, someone connected me with the Association of People Living with HIV APLHIV. For the first time, I received accurate information, guidance, and emotional support. Later, my tests confirmed that I was also affected by TB, and treatment for both HIV and TB was started immediately. After completing one year of treatment, I successfully recovered from TB.

Even after recovery, one fear remained in my heart, the fear for my children. I constantly worried about their health and future. Thankfully, their test results were clear, and that moment brought me immense relief and gratitude.

But my journey did not end there. Deep inside, I carried a strong desire to support people facing struggles similar to mine. Through APLHIV, I learned about ACT! PK and became connected with its work. Today, I continue supporting affected communities by providing guidance, sharing information, and helping connect people to counseling services through the Islamabad helpline.

As I began informing others about ACT! PK and available support systems, I realized that the support I once received was now reaching many others like me. That gave new meaning to my experience.

Through the Community Engagement Strategic Initiative CE SI, implemented by ACT! PK in coordination with APLHIV and supported by APCASO, communities are receiving greater awareness, counseling, and support through a community based approach. These efforts are helping people feel less isolated and more empowered to seek care and guidance.

Today, my message is simple. No one should suffer alone because of fear, stigma, or lack of awareness. With timely support, understanding, and compassion, lives can change. Projects like these should continue so that more people can find hope, support, and the courage to move forward.



تنویر احمد - عزم و حوصلے سے ٹی بی کو شکست دینے والے فرد کی کہانی

ملتان، پنجاب

اکتوبر 2018 میں میری زندگی اس وقت بدل گئی جب میں شدید کھانسی، بخار اور مسلسل گرتے ہوئے وزن کا شکار ہو گیا۔

کئی طبی معائنوں اور تشخیص میں تاخیر کے بعد، بالاخر میرا ٹی بی (TB) کا ٹیسٹ ہوا جو مثبت آیا۔ اس کے فوراً بعد، مجھے ملتان کے ڈسٹرکٹ ہیڈ کوارٹرز ہسپتال ریفر کر دیا گیا، جہاں مجھے زندگی بدل دینے والی ایک اور خبر ملی کہ میں HIV کے ساتھ بھی جی رہا ہوں۔

اس لمحے میں اندر سے بالکل ٹوٹ چکا تھا۔ میں اس وقت اپنی والدہ کی دیکھ بھال کر رہا تھا جو کینسر کے علاج کے مراحل سے گزر رہی تھیں، اور میں تصور بھی نہیں کر سکتا تھا کہ خوف اور اتنی بڑی ذمہ داری کے بوجھ کے ساتھ زندگی کو کیسے آگے بڑھایا جائے۔ میں نے خود کو سب سے الگ تھلگ کر لیا اور شدید ذہنی و جذباتی دباؤ کا شکار ہو گیا، جبکہ میری بیماری سے جڑے معاشرتی رویوں اور بدنامی کے خوف نے صورتحال کو مزید مشکل بنا دیا۔

پھر آہستہ آہستہ میرا یہ سفر بدلنا شروع ہوا جب میرا رابطہ APLHIV سے ہوا۔ کونسلنگ، اپنے جیسے دوسرے لوگوں کے ساتھ بات چیت اور ان سے ملنے کے بعد جو ان حالات کے باوجود ایک مثبت زندگی گزار رہے تھے، میرے اندر امید کی کرن دوبارہ جاگی۔ مجھے احساس ہوا کہ میں اس سفر میں تنہا نہیں ہوں، اور مناسب علاج کے ساتھ زندگی کو عزت و وقار کے ساتھ گزارا جا سکتا ہے۔

جیسے ہی میری صحت بہتر ہوئی، میں نے عزم کیا کہ جو خوف اور تنہائی میں نے جھیلی ہے، وہ کوئی دوسرا محسوس نہ کرے۔ میں نے ٹی بی (TB) اور HIV کا سامنا کرنے والے لوگوں کی مدد کرنا شروع کر دی، ان کے ساتھ درست معلومات شیئر کیں اور علاج و رہنمائی کے حصول میں ان کا ساتھ دیا۔

بعد ازاں ACT ! PK کے ساتھ جڑنے سے میں نے کمیونٹی کی سطح پر کی جانے والی امدادی کوششوں کا حصہ بن گیا۔ ان اقدامات نے لوگوں کو یکجا کیا، آگاہی کو مضبوط بنایا اور متاثرہ کمیونٹیز کو ان کے حقوق، علاج کے بہتر طریقہ کار اور دستیاب امدادی نظام کو سمجھنے میں مدد فراہم کی۔

مجھے قومی سطح پر ہونے والی اہم گفتگو اور مباحثوں میں بھی شرکت کا موقع ملا، جن میں گلوبل فنڈ (Global Fund) کے مشاورتی اجلاس شامل ہیں۔ وہاں ہم نے کمیونٹی کی آواز اور ان کے تجربات کو آگے پہنچایا تاکہ ٹی بی (TB) اور HIV کے سدباب کے لیے مستقبل کی منصوبہ بندی اور فنڈنگ کے نظام کو مزید بہتر بنایا جا سکے.



آج میں اپنے اندر اور اپنی کمیونٹی میں ایک واضح تبدیلی دیکھتا ہوں۔ جسے میں کبھی اپنی زندگی کا اختتام سمجھ رہا تھا، وہ اب ایک با مقصد سفر بن چکا ہے۔ اب میں دوسروں کے ساتھ کھڑا ہوتا ہوں تاکہ کوئی بھی خوف یا خاموشی کے سائے میں خود کو تنہا محسوس نہ کرے۔ میری یہ کہانی محض ایک جدوجہد کی نہیں، بلکہ صحت یابی اور خود کو ایک نئی طاقت میں ڈھالنے کی داستان ہے۔

Turning Struggle Into Purpose

Tanveer Ahmad

In October 2018, my life changed when I started suffering from severe cough, fever, and continuous weight loss. After several medical visits and delays in diagnosis, I was finally tested for Tuberculosis (TB), which came back positive. Soon after, I was referred to the District Headquarters Hospital in Multan, where I received another life changing news, I was also living with HIV.

At that moment, I felt completely broken. I was caring for my mother, who was undergoing cancer treatment, and I could not imagine how to continue life with both fear and responsibility on my shoulders. I isolated myself and struggled emotionally, while stigma around my condition made things even harder.

Slowly, my journey began to change when I connected with the Association of People Living with HIV (APLHIV). Through counseling, peer support, and meeting others who were living positively with similar conditions, I started to regain hope. I realized I was not alone, and that treatment and life could continue with dignity.

As my health improved, I decided I did not want others to experience the same fear and isolation. I began supporting people facing TB and HIV, sharing information and helping them find guidance and care. Later, through ACT! PK and the Community Engagement Strategic Initiative (CE SI), implemented in coordination APLHIV and supported by APCASO, I became part of community-based support efforts. These initiatives brought people together, strengthened awareness, and helped communities understand their rights, treatment options, and available support systems.

I also had the opportunity to participate in national level discussions, including Global Fund consultations, where community voices were shared to improve future planning and funding for TB and HIV responses.

Today, I see change in myself and in my community. What once felt like the end of my life has become a journey of purpose. I now stand with others so that no one feels alone in fear or silence.

My story is one of struggle, recovery, and transformation into strength.



ٹی بی کے ساتھ میرا سفر: خوف سے امید اور خدمت تک

ٹی بی (تپ دق) کے ساتھ میرا سفر دردناک، جذباتی اور زندگی بدل دینے والا تھا۔ 2007 میں، میرے شوہر شدید بیمار ہو گئے۔

چند طبی ٹیسٹوں کے بعد ہمیں معلوم ہوا کہ وہ ایچ آئی وی (HIV) کے ساتھ جی رہے تھے اور انہیں ٹی بی بھی ہو گئی تھی۔ وہ دن ہمارے خاندان کے لیے انتہائی مشکل تھے۔ اس سے پہلے کہ ان کا ٹی بی کا علاج صحیح طریقے سے شروع ہو پاتا، انہیں ایچ آئی وی اور ٹی بی دونوں کی وجہ سے امتیازی سلوک اور بدنامی (اسٹگما) کا سامنا کرنا پڑا۔ معاشرتی رویوں اور مدد کی کمی کے باعث ان کا علاج مکمل نہ ہو سکا اور بالاخر میں انہیں کھو بیٹھی۔ اس وقت مجھے ان بیماریوں کے بارے میں نہ تو صحیح معلومات تھیں اور نہ ہی سمجھ، لیکن اس سانحے نے میرے دل میں ایک گہرا خوف بٹھا دیا۔ میں اکثر سوچتی تھی کہ کاش اگر بروقت علاج اور سہارا مل جاتا تو شاید حالات مختلف ہوتے۔

سالوں بعد، میری اپنی صحت بھی بگڑنے لگی۔ میری والدہ نے مجھے ٹیسٹ کروانے کا حوصلہ دیا، اور ٹیسٹ کے بعد معلوم ہوا کہ میں بھی ایچ آئی وی مثبت (HIV Positive) ہوں۔ یہ سن کر مجھے اپنے شوہر کی تکلیف دہ یادیں ستانے لگیں اور میں اپنے مستقبل کو لے کر شدید خوف اور بے یقینی کا شکار ہو گئی۔

اس مشکل وقت میں، کسی نے میرا رابطہ 'ایسوسی ایشن آف پیپلز لونگ ود ایچ آئی وی' (APLHIV) سے کروایا۔ زندگی میں پہلی بار مجھے درست معلومات، رہنمائی اور جذباتی سہارا ملا۔ بعد میں، میرے ٹیسٹوں سے یہ بھی تصدیق ہو گئی کہ میں ٹی بی سے بھی متاثر ہوں، جس پر ایچ آئی وی اور ٹی بی دونوں کا علاج فوری طور پر شروع کر دیا گیا۔ ایک سال کا علاج مکمل کرنے کے بعد، میں الحمدللہ ٹی بی سے مکمل طور پر صحت یاب ہو گئی۔

صحت یابی کے بعد بھی میرے دل میں ایک ڈر باقی تھا— اپنے بچوں کی صحت اور مستقبل کا خوف۔ شکر ہے کہ جب ان کے ٹیسٹ کروائے گئے تو نتائج منفی (کلیئر) آئے، اور اس لمحے مجھے بے پناہ سکون اور خدا کا شکر ادا کرنے کا موقع ملا۔

لیکن میرا سفر یہاں ختم نہیں ہوا۔ میرے اندر ایک شدید خواہش تھی کہ میں ان لوگوں کا سہارا بنوں جو میری طرح کی مشکلات سے گزر رہے ہیں۔ APLHIV کے ذریعے مجھے ACT! PK کے بارے میں معلوم ہوا اور میں ان کے کام سے منسلک ہو گئی۔ میں اپنے جیسے لوگوں کو جوٹی بی سے متاثرہ ہیں انہیں آگاہی اور سا ئیکوسو شل سپورٹ خود مل کر (براہ راست) دیتی ہوں اور مزید پروفیشنل خدمات کے لیےان کو APLHIV کی فری ہیلپ لائن سے رہنمائی کے لیے کنیکٹ کراتی ہوں



جب میں نے دوسروں کوACT! PK اور دستیاب امدادی نظام کے بارے میں بتانا شروع کیا، تو مجھے اندازہ ہوا کہ جو سہارا کبھی مجھے ملا تھا، وہ اب میری طرح کے کئی اور لوگوں تک پہنچ رہا ہے۔ اس بات نے میری زندگی اور تجربے کو ایک نیا مقصد دے دیا۔

'کمیونٹی اینگیجمنٹ اسٹریٹجک انیشی ایٹو' (CE SI) کے تحت، جسے ACT! PK نے APLHIV کے تعاون سے اور APCASO کی مدد سے نافذ کیا ہے، کمیونٹیز کو ایک علاقائی اور باہمی طریقہ کار کے ذریعے آگاہی، کونسلنگ اور ترجیحی امداد فراہم کی جا رہی ہے۔ ان کوششوں کی بدولت لوگ خود کو تنہا محسوس نہیں کرتے اور علاج و رہنمائی حاصل کرنے کے لیے بااختیار اور باحوصلہ ہو رہے ہیں۔

میرا اہم پیغام:

آج میرا پیغام بالکل سادہ ہے: خوف، بدنامی (اسٹگما) یا معلومات کی کمی کی وجہ سے کسی کو بھی تنہائی میں تکلیف نہیں سہنی چاہیے۔ بروقت مدد، ہمدردی اور سمجھ بوجھ کے ساتھ زندگیوں کو بدلا جا سکتا ہے۔ اس طرح کے منصوبے جاری رہنے چاہئیں تاکہ مزید لوگ امید، سہارا اور آگے بڑھنے کا حوصلہ پا سکیں۔

LESSONS LEARNED

When the project was first envisioned, it was set against an entirely different backdrop than the one we find ourselves in now. The shift over the past two years has been monumental, causing an unprecedented transformation in the global health landscape particularly funding for civil society engagement. We continue to be faced with the shrinking space for communities and civil society, alongside major funding cuts on a scale that few could have anticipated or were prepared for. These cuts have had devastating consequences, costing civil society organisations and community members their jobs and livelihoods and threatening to undo years of progress in ensuring that communities remain at the centre of health responses.

While these sudden shifts exposed the fault lines and fragility of our health systems and responses, they also revealed the resilience of the human spirit and the determination to keep the fight alive. Inspired by this resilience from the communities we work with, we have had to re-orient the implementation of this project. While adapting our activities to an evolving and increasingly challenging landscape, we have remained steadfast in our commitment to the project's purpose and objectives which is to champion community engagement, leadership and voice in TB responses.

TB networks in the three project countries were established in response to the identified need for a formalized platform to convene and strengthen the voices of people affected by TB, and to channel these voices into advocacy efforts aimed at influencing policies, the national and Global Fund TB response. The vision was for these nascent networks to continue growing in strength and capacity beyond the project period, supported by funding sources beyond the Global Fund. The primarily source was the Challenge Facility for Civil Society (CFCS), the Stop TB Partnership's flagship grant-making and capacity-building mechanism for grassroots communities, TB survivors, and civil society organizations (CSOs). However, the termination of USAID contracts in 2025 plunged these critical funding mechanisms for TB-affected communities into uncertainty, significantly jeopardizing the sustainability plans for these TB networks. These developments while unprecedented have provided crucial lessons on the importance of flexibility and adaptability in programming, enabling timely and agile responses to evolving circumstances and emerging needs.



RECOMMENDATIONS

1. CONTINUED AND SUSTAINED INVESTMENT IN COMMUNITY ENGAGEMENT. Investing in community engagement in the TB response is a long-term commitment that requires sustained effort and resources. Given the mobility of TB-affected communities, particularly as communities relocate across provinces in search of employment and livelihood opportunities, there is likely to be significant turnover among community members engaged in programme activities. Therefore, capacity-building efforts must be continuous, with regular training and skills development to ensure that community members are equipped to sustain and strengthen their engagement in the TB response.

2. DEDICATED INVESTMENT FOR ORGANISATIONAL DEVELOPMENT (OD). Investing in capacity training in OD and governance is essential to equip community members with the knowledge and skills needed to operate effectively within formal organisational structures and governance systems. While governance approaches should be contextualised to each country's specific needs and operating environment, workplan and budget should incorporate organisational development and governance capacity-building as an integral component to strengthen TB networks, support effective leadership, and promote long-term sustainability.

3. FACILITATE CROSS-DISEASE AND CROSS-CONSTITUENCY COLLABORATION. While integrated health responses are widely championed, this integration is not always reflected in the actual practices of civil society organisations and communities. The engagement plan modality initiated by the CE-SI demonstrated the potential to bridge these gaps, enabling unprecedented collaboration across disease areas and community constituencies. Despite implementation challenges, this modality is worth sustaining and investing in, as it creates valuable opportunities for cross-learning, strengthens collaboration among diverse stakeholders, and advances a more integrated, community-led health response. In Nepal, this engagement enabled the active participation of transgender communities in the TB response through the collaboration between Trishuli Plus and the Blue Diamond Society (BDS). Similarly, in Mongolia, the implementation of the CE-SI engagement plan fostered successful collaboration among TB-affected communities, sex workers (represented by Perfect Ladies), and young people (represented by Youth Lead Mongolia), demonstrating the value of cross-constituency partnerships in strengthening community engagement in the TB response.

4. STRENGTHEN CROSS-COUNTRY LEARNING AND KNOWLEDGE EXCHANGE. Cross-country learning among project partners offers significant value and should be leveraged more systematically. During the project, partners from the three participating countries benefited from opportunities to exchange experiences and learn from one another through a cross-country visit and a joint meeting. Building on these experiences, future programmes should integrate structured and ongoing learning opportunities into their design, using diverse approaches such as case story sharing, webinars, peer-to-peer exchanges, and joint learning sessions. This would enable partners to share good practices, learn from each other's challenges, and adapt successful approaches throughout the project cycle.

5. EXPANDING TB NETWORKS THROUGH CROSS-SECTOR ALLIANCES. There is value in expanding TB networks to include allies working on complementary issues, such as human rights and mental health, to broaden perspectives and strengthen the response. Engaging these allies can help ensure that TB programming incorporates a more holistic, rights-based and person-centred approach, while fostering cross-sector collaboration and enabling more effective engagement with TB-affected communities.



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66/5, Tower 33, Sukhumvit 33 Road,
Klongton Nuea, Wattana Bangkok, 10110 Thailand

www.apcaso.org