POSITIVE DIARIES
STORIES OF PEOPLE LIVING WITH HIV IN PAKISTAN
Photography is a highly powerful tool to depict reality. It narrates stories through lights and colors. It captures people’s feelings through their expressions. It silently gives a voice to those that have no means to make their stories heard.

For the very first time, people living with HIV in Pakistan have been empowered to share their life experiences with the outside world.

Civil society and communities have been the main engine of the AIDS response since the beginning of the epidemic. Today, their contribution and support are still essential for advocating for a robust response to the epidemic, for delivering quality services and for tackling HIV-related stigma and discrimination.

Positive Diaries - Stories of people living with HIV in Pakistan is a wakeup call to raise awareness of the AIDS epidemic and HIV-related stigma and discrimination. Ultimately, we hope that the stories courageously narrated through these images will inspire other people living with HIV in Pakistan to get out of isolation and despair and to live their lives to the fullest.

This is the message we wish to relay as we celebrate the 70th anniversary of the United Nations, the organization that embodies the universal values of solidarity, equality and justice. In today’s world there is no room for discrimination and we can all contribute “to reaffirm faith in fundamental human rights, in the dignity and worth of the human person”, including those living with HIV.

Only by building solid partnerships can we achieve the goals of the United Nations Charter: this project was made possible by the innovative vision of UNAIDS and of the United Nations Information Centre and with the support and trust of the National AIDS Control Program and the civil society.

Our most heartfelt gratitude goes out to our friends living with HIV who bravely broke their silence and shared their stories hoping to contribute to a better future, for us and for future generations.

Vittorio Cammarota,
Director, United Nations Information Centre
FOREWORD

Like other Asian countries, Pakistan is following a comparable HIV epidemic trend having moved from ‘low prevalence, high risk’ to ‘concentrated’ epidemic in the early to mid-2000s. The estimated number of HIV positives in the country stands at 94,000.

Pakistan’s epidemic is primarily concentrated among two of the key population groups driving the epidemic in the country. These are People “Who Inject Drugs” with a national prevalence of 27.2% followed by “Transgender Sex Workers” standing at 5.2% and then 1.6% among Male Sex Workers. Fortunately the prevalence in “Female Sex Workers” still remains low at 0.6%. Currently People Who Inject Drugs produces the bulk of new infections, and will continue to produce the same absolute number of new infections and the largest contributions of new infections over time are by transgenders. In Pakistan, the cities of Faisalabad, Karachi and Lahore each have much higher HIV prevalence among people who inject drugs than the national average.

Prevention is still the priority when it comes to tackling the HIV and AIDS epidemic in Pakistan and it is essential that each person living with the disease receives the care and support they deserve from all key stakeholders. We have to act now! The next five years provide a fragile window of opportunity to fast-track the response and to make investments, otherwise the cost of disease burden will be higher in coming years.

The Government of Pakistan along with UNAIDS is striving hard to engage all stake holders especially Civil Society Organizations, corporate sector with multi-sectoral approach to join hands in the endeavour to curb the HIV epidemic in the country.

The stories in this booklet are all real and the brave people who chose to share these reflect the complex socio-cultural factors that have contributed to the spread of the virus. Each testimony is unique and serves to help reduce stigma and discrimination that people living with HIV continue to face.

Dr. Abdul Basier Khan Achakzai, National Program Manager, National AIDS Control Programme (NACP)

INTRODUCTION

It has been the most serious epidemic the world has seen for the past three decades. But through activism and research it became one of the most effective global movements of this generation, we are now able to say with confidence, that ending the AIDS epidemic is possible. And we are embarking on a Fast-Track strategy to achieve this goal by 2030.

Around 35 million people were living with HIV worldwide by the end of 2013 but new HIV infections were estimated at 2.1 million, that’s 38% lower than in 2001. The number of AIDS-related deaths also continues to decline, down by 35% from the peak in 2005. There is, however, much work that still needs to be done to accelerate progress to end the epidemic and new Fast-Track targets have been established in the post-2015 era. These aim to transform the vision of zero new HIV infections, zero discrimination and zero AIDS-related deaths into concrete milestones and end-points so that no is left behind. Through this strategy, we can bring health, equality, social justice and dignity for all key populations in Pakistan.

What’s also new is that for the first time, there is a global consensus on key goals. These aim for 90% of people living with HIV knowing their HIV status, 90% of people who know their status are receiving treatment and 90% of people on HIV treatment having a suppressed viral load so their immune system remains strong and they no longer spread the infection. Meeting these ambitious Fast-Track targets will also avert 21 million AIDS-related deaths by 2030. Sustainable Development Goals provide an opportunity to quicken the pace of ending AIDS by 2030 because if we fail to invest now, we risk a rebound in the epidemic with catastrophic human and financial consequences.

We have a fragile five-year window to build on the rapid results that have been made so far. It is time for everyone living with HIV and AIDS to be counted and reached and to ensure that human rights of all people are protected.

Dr. Mamadou L. SAKHO, UNAIDS Country Director for Pakistan & Afghanistan
Nazir Masih

Nazir is the CEO of New Lights AIDS Awareness Society in Lahore. He is 55 years old.

“...My story with HIV has been a long journey. It was back in 1990 in Abu Dhabi where I had been living for 14 years that I found out about my HIV status. Luckily, my wife and five children did not test positive for HIV, but we returned to Pakistan shocked, fearful and uncertain about what would happen to me. The environment in Pakistan was very challenging at that time. There was a complete denial of the HIV epidemic and I had no support other than that of my wife. To make matters worse, a journalist published my photo and name. So I became the first person living with HIV to go public about my status in a place where there was no medical help and no support network. In 1994, I was introduced to a Catholic priest from the Philippines, who visited Pakistan to work with HIV-positive people. I worked with him for four years but at that time we were able to find only five people living with HIV. People preferred to live in silence. My inspiration to form a Community-Based Organization (CBO) took root when in 1997 UNAIDS sent me abroad to share my experience. My interactions there encouraged me to make connections with HIV positive people and create my own organization. We not only provided medical treatment and food to people living with HIV but also worked with them to find others like us who were alone and in need of support. In 2003 we were able to introduce antiretroviral medicine (treatment for HIV) in Pakistan for the first time. Today we are supporting about 1,000 people in a country where no one was even willing to talk about HIV a few years ago. HIV is a problem of human beings and it is not an issue of any particular religion or nation. That is why hurdles and threats cannot deter me from the path of helping those in need. I will not stop, come what may because this is my destiny.”
55

1990 میں ایک آئیو سی ایک سی کے گھر کی تکنیکیں کی گئیں جن کے ساتھ 14 سالوں میں دنیا کے ہر جا کے خواتین میں نیوڈیالیز کے لئے خوش منے کا کمی سمجھا جا سکتا ہے۔ ایک دنیا بھر میں، خواتین کی چند ہزاروں نے اپنی کمی کا نشان دہانہ کیا ہے جنہوں نے خواتین کے لئے متعدد مضبوطات کی تصدیق کی۔

2003 میں، جب ایک ہندوستانی خواتین کو میڈیکل کینٹر کے لئے نیوڈیالیز کی امکان پیش کی گئی، انھوں نے اپنے بچوں کو دکھایا کہ امکانوں کو نہ تنگی کرنے اور حلبہ کا جنگ سازی نہیں ختم کرنا ضروری ہے۔ اس کا نتیجہ ہے کہ اب بہت زیادہ خواتین نے اپنے سلہہ کی تصدیق کی۔
MUHAMMAD YOUNIS

Younis is 24 years old. He is a barber.

“It took the doctors a while to find out what was wrong with me. Six years ago I was diagnosed with HIV in Islamabad.

The main challenge for me is to continue to make a living working as a barber. I have to be watchful to prevent my customers from getting HIV from me. I take as many precautions as I can which includes not going to work when I have cuts on my hands. I have to wait for my hands to heal and during those days I lose money.

I tried my hand at masonry but my allergy to cement got in the way.”

"
Can you imagine the pain of a mother who was not even allowed to care for and love her children? It was when I lost my husband to HIV six years ago that I started taking medicine. I wanted to be well for my children, but my mother in law isolated me. She kept my children away from me. However, my children never stopped loving me. Rather they care for me more after their father passed away. Their love is the light of my life.
It was six years ago that I found out about my HIV positive status. I had a tragic miscarriage and needed a blood transfusion. I felt alone and scared. I did not even know how to help myself. Had it not been for my family I cannot even imagine where I would be and what would be my condition. It’s a relief that my in-laws treat us well. My husband and son are also living with HIV too but luckily my daughter is not. I am pregnant again and this is why I never skip my medicine and go regularly for a medical checkup. I take my medication twice a day and so I feel great.
Now 45 years old, Javed has changed his lifestyle.

One night I was kidnapped and raped by a group of men and that was the day I decided to quit dancing for money at a circus. Last summer I found out that I was HIV positive. The social isolation I have had to face would be unbearable if it wasn’t for the support of my wife. I am devoted to her and the sewing machine now. I am happy to access ARVs. It makes me feel healthy and active and so I make it a point to take my medicines regularly. Without the ARVs and the love of my children I wouldn’t be able to lead the healthy life that I live now.
If you ask me I can say for sure that the major cause of the spread of HIV is lack of awareness which results in risky behaviour. I believe the local doctor used unsterilized needles to treat me. Intentionally or unintentionally, he spread HIV to at least 100 other people in the community. Had it not been for the kind and understanding people working for an HIV community group, my wife would probably have died. The improvement in my wife’s health condition encouraged many other people to get treatment. My wife and I know and understand the importance of taking ARVs regularly and we happily promote this message to many other people. Medicine helps me feel strong and energetic. My appetite has improved too. I am also able to go out with friends. I derive hope from reaching out to those in need. I am ready to go out and help others even if it is one in the morning.

Tanvir Ahmed
Tanvir is a driver. He is 40 and lives in Jalalpur Jattan.
ALLAH RAKHA

44-year-old Allah Rakha lives with his 5 children and wife who are HIV negative. He is a mason.

I learned of my HIV positive status when I was working in a state in the Gulf and I applied for a visa extension after staying for three years. I was deported and then was treated badly by my community when I returned. The situation took its toll on me. However, my family has been very helpful in enabling me to come to terms with my situation. Medicine has been a true saviour. When I look back I agree that prevention is better than treatment. Although I realized this late, I am happy for people who use precautions because they do so to protect themselves and others. I now feel privileged to be in a situation where I am able to raise awareness about HIV prevention. The feeling of being a source of helpful information for others gives me relief and satisfaction.
“After I had a tooth extraction, I was never well again. My face was swollen and I had a high fever. In 2007 I was tested and was diagnosed as HIV positive. My husband also tested positive. It was the toughest time in my life, but I consider myself lucky that my in-laws stood by us. They showed me love and care which was a great encouragement against the judgmental & discriminatory attitude of the community. With medicine my condition improved. It is sad that even sometimes in hospitals we faced isolation and stigma. I decided to raise awareness on HIV and let a community organization set up a medical camp in our home. The reactions were difficult. Many people who tested positive were in disbelief and accused us of setting up the camp for getting publicity. I feel they acted that way because they lacked awareness. I will not give up on raising awareness no matter what people say. I also actively promote the importance of medication. I believe taking ARVs regularly means we will be able to live. I love to live for not only myself but for others. I know that many people continue to live with HIV in silence. Silence on HIV needs to be broken because it endangers everyone. I will continue to raise my voice until my last breath.”
Sonja MUSHTAQ

Sonja is 24 years old.

"I wish I could say that I have recovered from the shock of finding out that I am living with HIV. My husband is also HIV positive and we believe the virus was transmitted to him during a dental procedure. Although ARV medicine has stabilized my husband’s condition, he is worried about me and the child I am carrying. I am five months pregnant and following my physician’s advice on how to ensure my baby is born HIV-free. I am on treatment so that my child should not born with HIV.

My two year old son is healthy and the friends in my treatment center taught us that we have every reason to live this life holding our heads high."
30-year-old Mudassar is unemployed.

After I got shot at a friend’s wedding during celebratory aerial firing I was taken to a doctor’s assistant. My wound was not treated properly and I remained in constant pain. I became addicted to painkiller injections. Eventually when I went to the hospital for proper treatment I had to undergo a blood transfusion. I believe that is when I got HIV as I don’t think the blood was properly screened. I am now on ARVs. The compassion of a community support group has won my heart. It also helps me maintain my health and I am interested to live the gift of life.
When a medical camp was set up at my home to conduct HIV tests about 100 people were diagnosed HIV positive. My community does not know how this happened but they strongly suspect the local doctor, who was known to treat people who inject drugs and people who worked abroad... When I was told I was HIV positive I did not know what this meant. My family was tested and my heart melted into tears when my husband and two children also tested positive. Luckily we were able to access treatment. I have been taking medicine for nine years now. The medicine is so effective that I do not even feel that I am HIV positive. Now I go door to door to raise awareness about the importance of getting tested for HIV. My children are my reason to live.

Bilquis works in an NGO, she is 40 years old.
Asif Hussain

Asif is 27 years old. He is unemployed. He has known about his status since 2007.

"Why has my father abandoned me? I have not been able to find an answer to this question. It could be because I have HIV or perhaps he is angry because I had sex without being married. When I was younger I went abroad for work. I fell for this young woman from another country. We always had unprotected sex. In 2007 I found out about my HIV positive status. We broke up. I am close to my mother, who takes care of me and reminds me about the importance of taking my medicine on time. It really helps."
Can I hold the doctor responsible for my health? I believe he used dirty and unsterilized needles for treating the abscess on my leg. I was married off, when I was just 14 and lost two of my five children but I still feel young at 30. I feel I have the support network that I need in the form of my family. The medical treatment that I am receiving not only keeps me well but also is a source of motivation for moving forward in my life. I do not wish to pass on HIV and that is why I am happy that I undergo regular testing and am adherent to ARVs. What keeps me alive is the hope I have for the future of my three girls. I am sure they will have a good life if I am able to give them an education. That is now my aim in life.
MOHAMMAD NAZEER

Nazeer is a book binder and lives with his sister. He was one of the first five patients to access ARV medicine in Pakistan. He is 44 years old.

“It’s a miracle that I am still alive. Life for me almost ended 14 years ago when after working abroad for a decade, I found out that I was HIV positive. I was severely stigmatized upon my return home. Friends and relatives did not want to come near me. I was left alone. ARV medicine introduced in 2003 improved my health. I have survived and that is why I want to emphasize that adherence to treatment really helps. That is my message.”

“44 مہمان نازیر کا مذہب اور اوریجین میں تنازعات کے باوجود، 2003ء میں اپنی آزمونوں کے اختتام پر ARV ڈارنگ کو اپنی صحت سے بہتر بنانے کیلئے اپنے طبیب سے مفتی کیا ہوئے تھا، لیکن اس گروپ کی پہلی سال منا کرنا پڑا. 2003ء میں میں نے اپنے طبیب سے ARV ڈارنگ کو اپنے خانے کے لئے پینا شروع کیا تھا۔
Irfan lives in a city and is a television cable operator. He is single at 24 years.

When I was younger I enjoyed the thrill that my job as a television cable operator offered. I used to go door to door, installing equipment in a neighborhood where there were many sex workers. I started having unprotected sex with sex workers. At one time I had 15 sexual partners. For twelve years I also used drugs. One day in 2013, I was picked up by a support group from a graveyard where I lay unconscious. The support group encouraged me to take and HIV test and that is how I learnt about my status. I wish I were more aware of how a risky life style could lead me to this situation.
POSITIVE DIARIES
STORIES OF PEOPLE LIVING
WITH HIV IN PAKISTAN