



Who we are: Pediatric HIV/AIDS Treatment Support (PATs) is a nonprofit organization based in Boston, Massachusetts working to build community partnerships to promote the health, wellbeing, and prosperity of HIV-positive children in China. Our vision is to empower local communities with the skills and knowledge to provide quality and comprehensive care to 37 HIV-positive children in Anhui and Henan provinces. All US operations are run entirely on a voluntary basis, while paid staff are based in China and work directly with the children.

Mission: PATs aims to promote the health of HIV-positive children in four communities in Anhui and Henan provinces in China. Believing that community-based care is essential to providing sustainable, high-quality, comprehensive care to HIV-positive children, PATs builds the capacity of local community health workers and families to deliver appropriate services, including anti-retroviral treatment, nutrition, HIV/AIDS education, and psychosocial support.

Background: PATs was established in 2007 in response to an urgent and on-going situation: the inadequate care of HIV-positive children in rural China. To leverage local participation and commitment to this issue, PATs made the strategic decision to partner with the AIDS Orphan Salvation Association (AOS), a local Chinese NGO which supports over 600 children affected by HIV/AIDS and their families throughout Anhui and Henan provinces. AOS is the leader in community care for children *affected* by AIDS in central China and has excellent relationships with local doctors, ministries of health and communities. Recognizing that 16 of the AOS children were *infected* with HIV/AIDS and were not receiving needed medical support due to financial and technical limitations, PATs launched a pilot program to test the efficacy of using trained community health workers (CHWs) to provide care, education, nutrition, and adherence support to these children and their caretakers. Data from the pilot program demonstrated that the CHW model resulted in 98.5% adherence to anti-retroviral treatment – a huge success given the major challenges faced by children in adhering to treatment, such as taking medication at precise times, receiving proper nutrition, and managing side effects like nausea and diarrhea.

PATs Achievements in China:

- The program has grown from the original 16 children to include 37 HIV-positive children in 4 counties and 2 provinces.
- During the first pilot year, treatment adherence was 98.5% in intervention areas among the initial 16 children.
- Links with local doctors and the local health system have been strengthened through regular communication with community health workers.
- Caretakers are able to play a critical role in the child's treatment.
- Children are noticeably happier, more social, and better adjusted.
- Children not yet receiving treatment are closely monitored to determine need.

Status of HIV/AIDS in China: The WHO and UNAIDS have jointly estimated that there are approximately 650,000 people currently living with HIV in China, though these numbers are likely vast under estimates due to limitations in surveillance, testing, and reporting. In the early 1990s, hundreds of



thousands of peasants in central China, particularly the provinces of Anhui, Henan, and Hubei, contracted HIV when they sold blood to alleviate their poverty. Many blood collecting stations used high risk procedures, such as reusing needles without sterilization and plasma pooling among donors of the same blood type. Infection rates rose rapidly – reaching as high as 60% in some villages – as farmers returned repeatedly to sell their blood for \$4 and \$5 per pint, an enormous amount of money for this population. Without intervention, the number of cases of HIV/AIDS is expected to grow to 2.3 – 4.5 million by 2015.

HIV-positive children face severe health risks primarily because caretakers are not educated about when to introduce anti-retroviral medication, how to promote adherence, and how to pursue support from the local health system. As a result, children are at risk of defaulting on treatment, developing drug resistance, suffering from undiagnosed opportunistic infections, or dying. In addition to the inherent health risks, HIV-positive children face additional hardships from the pervasive stigma surrounding HIV/AIDS. Often, children are not permitted to attend school due to fears among parents and educators about contracting the disease. In schools and communities, other children refuse to play or stand near them, or taunt them.

The PATS Community-Based Care Model: PATS has expanded beyond the initial 16 children to support 37 HIV-positive children, and is working with local partner AOS to continue to expand this program to include all identified HIV-positive children referred to the program in Anhui and Henan provinces. PATS' pediatric HIV treatment model is built upon the following core approaches, all of which are rigorously monitored and evaluated to measure their efficacy and guide program implementation:

- **Community Health Workers:** CHWs play a critical role in ensuring drug adherence and monitoring the child's health through regular home visits. The CHW takes the child's temperature, height and weight, checks for rashes, and asks the child or caretaker about diarrhea, coughs, appetite, and mood. Any irregularities are immediately reported to the child's doctor, and discussed at follow-up meetings held monthly. CHWs also count pills during home visits to assess whether any doses have been missed, and remind the doctor about any changes in height and weight that might signify the need for changes in dosage levels.
- **Access to Medication:** First line pediatric anti-retroviral (ARV) formulations are provided to all PATS children who need them through a partnership with the Clinton Foundation and the Chinese Ministry of Health. Local doctors trained in HIV/AIDS treatment dispense ARVs to caretakers who are responsible for administering the medication at home with the support of CHWs. For children who have developed treatment resistance, second line drugs are required, yet most of these drugs are either unavailable in China or are prohibitively expensive. PATS has been fortunate to receive some donated second line drugs from AID for AIDS, a New York



based NGO, and works closely with CHWs to ensure that all drugs are re-ordered on time and in the correct dosages to prevent treatment interruption.

- **Nutritional Support:** Adequate nutrition is essential to the health and wellbeing of children living with HIV/AIDS as it thwarts HIV disease progression, promotes a healthy immune system, and reduces the incidence of opportunistic infections. Nutrition requirements are 50-100% greater for HIV-positive children compared to those of uninfected children. As such, PATS provides each child with a basic monthly food package which includes fruit, milk powder, bread, and crackers. In addition to this nutritional support, each household is provided with a modest monthly stipend in order to purchase fresh, nutritious food for the children each week.
- **Educated Caretakers:** PATS-supported CHWs regularly communicate with caretakers about the health of the children, review blood safety measures, and discuss adherence protocols. CHWs also works with the older children to ensure that they understand how to properly take the drugs. Even some of the younger children can explain exactly which pills they take, the dose, and the time. Helping children to play an active role in their own treatment is critical to ensuring adherence and preventing recourse to second line drugs.

Monitoring and Evaluation: Monitoring and Evaluation (M&E) is an essential aspect of the PATS program. Monitoring tracks the actual progress of the program against our projected goals while evaluation assesses program efficiency and effectiveness. Ultimately, M&E processes improve PATS' capacity to track children's health status on a regular basis, which informs future planning and development. PATS technical staff developed several M&E tools to record and assess indicators on the health of the children. Specifically, PATS created a form for CHWs to collect information during home visits and a supplementary questionnaire to capture more detailed information about adherence to ARVs, and the physical and mental health of the children. Ongoing M&E initiatives led by the CHWs include the maintenance of paper-based medical records and submission of quarterly reports that outline their activities with the children. Currently, PATS is developing a simple electronic medical record system to store demographic and clinical information. These initiatives build greater transparency and accountability for project activities, and provide an improved basis for evidence-based programmatic decision-making.

Participation: PATS is privileged to have the participation of leaders across many fields and disciplines. PATS has a very talented Board including doctors, academics, filmmakers and adoptive parents- each with a keen interest in helping children with HIV/AIDS in China and bringing their various skills, contacts and expertise to assist the program. The core PATS team includes about 25 US-based students and young professionals-many of whom are native Chinese speakers- who provide the main operational and fundraising support. Six full time paid local workers in China, 5 supervising local Chinese doctors, and a partnership with a local Chinese NGO active in the AIDS field are key to the program's success on the ground. Partnerships with the Clinton HIV/AIDS Initiative, the Fuyang, Anhui Ministry of Health and the Chinese Centers for Disease Control (CDC) allow PATS to enjoy



important support from high level stakeholders.

Demonstrated Leadership: Before PATS implemented its Community-Based Care model in Anhui and Henan provinces, using CHWs was not a common approach to adherence support for HIV-positive children in China, despite being a key approach implemented in many developing countries. PATS' pioneering efforts are achieving breakthrough impacts: PATS has been approached by both the Clinton Foundation and the local Ministry of Health with referrals of additional HIV-positive children who they feel would benefit from joining the program. In addition, PATS technical staff have partnered with the Chinese Centers for Disease Control (CDC) in Beijing to take the lead in developing a manual to strengthen a caretaker's ability to provide proper medical, nutritional, and psychosocial care to HIV-positive children. Currently in draft form, the manual, *Caring for an HIV-positive Child; a Guide for Community Health Workers and Caretakers*, has received positive feedback from the CDC and will be finalized in June 2010. This largely picture based manual will be a critical resource for people with low literacy who are responsible for delivering comprehensive care to HIV-positive children, giving them access to basic information about HIV/AIDS, treatment options, nutrition and hygiene, drug adherence, and how to contact CHWs or emergency services. Furthermore, it will foster standardized and sustainable services as provincial governments, private organizations, and NGOs adopt it for use in their own health programming.



Financial Support: The PATS Community-Based Care model has proven to be an effective and affordable approach to providing care and treatment support for HIV-positive children in isolated areas of China. Accordingly, the program is expected to expand further, as more children are identified and referred to the program. PATS is currently funded through the generous support of over 200 US-based donors including individuals, religious communities, NGOs, private companies, and foundations. **There is a waitlist of additional children who could benefit from joining the program.** If you are interested in sponsoring a child to ensure that their health needs are met, or providing critical general operating support to enable PATS to continue its lifesaving work please contact us at info@patskids.org or call us at 617-945-1847. **THANK YOU for your interest in PATS!**