

Persons Who Acquire HIV at Birth Need Better Support

People who acquire HIV from their birthing parent during pregnancy, childbirth, or during breast or chest feeding, as well as those who acquire the virus via blood transfusion before 5 years of age, are considered to be cases of perinatally-acquired HIV. Affected individuals themselves, however, are organizing under preferred terms of “Dandelions” or “Lifetime Survivors” which are the names of two networks they are forming to provide mutual support and advocacy. For brevity, we refer to Lifetime Survivors and Dandelions interchangeably for this whole group of people and we are not specifically referring to members of either the Dandelions Movement or the Lifetime Survivors Network. It is estimated that in 2019, there were 12,355 Lifetime Survivors out of roughly 1.2 million people with HIV in the U.S.

Preventing perinatal acquisition of HIV, sometimes called mother-to-child transmission or vertical transmission, remains a major concern globally. The United States, however, has essentially achieved what is considered virtual elimination. This represents a major policy success. According to the Centers for Disease Control and Prevention (CDC) in 2022, only 42 babies were born with HIV out of 3.7 million live births. **In the U.S., the focus on prevention, however, has not been met with a corollary commitment to supporting and addressing the unique needs of persons that acquired HIV perinatally.** Dandelions have been asserting themselves to establish their unique place in the HIV movement and to demand policy responses to address their unique challenges:

RECOGNIZE PERSONS BORN WITH HIV AS A VALID AND DISTINCT PART OF THE HIV COMMUNITY

- Federal agencies should collect and disseminate longitudinal data on clinical and social outcomes for Dandelions
- CDC should publish a data snapshot to highlight key demographic data about this population
- All HIV stakeholders should ensure that Lifetime Survivors are included in various forms of HIV stakeholder engagement

ADDRESS UNIQUE HEALTH CARE NEEDS ACROSS THE LIFESPAN

- The Ryan White HIV/AIDS Program (RWHAP) Part D and the AIDS Education and Training Centers (AETC) Programs should assess current capacity to support these individuals from childhood throughout the lifespan
- Aging advocacy organizations should collaborate with Lifetime Survivors to provide mutual support for improving HIV services across the lifespan

SUPPORT THE DEVELOPMENT OF PEER-LED ADVOCACY AND EDUCATION ORGANIZATIONS

- HIV coalitions and HIV services organizations should support the Lifetime Survivors Network and Dandelions, Inc. as vibrant and sustainable organizations

THE TIME IS NOW

Many people think of dandelions as weeds, but in many cultures around the world, they are a symbol of hope, healing and resilience. For the HIV community, they are beautiful flowers that brighten our diverse garden. As we continue to work to ensure that babies are not born with HIV, we need to redouble our efforts to lift up, listen to, and engage with Lifetime Survivors to ensure that they thrive across the lifespan.

WHAT MAKES A LIFETIME SURVIVOR?

Lifetime Survivors navigate many complex issues within their families, socially, and economically.

- Approximately two-thirds of Lifetime Survivors are Black and face institutional racism in addition to the challenges that often come with being HIV-positive.
- Many have parents with substance use disorders which has created added challenges during childhood, and many have lost parents, often at a young age.

Rather than being driven by loss and sorrow, however, the guiding force of a Lifetime Survivor is resilience. They are adept community-builders who cultivate a sense of family with one another as they pursue safety and wider recognition. Their deep-seated dignity drives the demand for more financially supported and well-informed care.

They combat stigma through creating visibility for themselves, bringing a chair to the table when a seat is not offered. Their ability to use their personal experiences and knowledge to drive impactful solutions makes them an integral part of both the community of people living with HIV and the HIV response.