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Women's Research Initiative on HIV/AIDS (WRI) 2026

WRI

Lifetime Survivors and Dandelions- Who We Are and How We Came to Be

Together, we can change the course of the HIV epidemic…one woman at a time.

#onewomanatatime

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WOMEN'S RESEARCH INITIATIVE ON HIV/AIDS

Lifetime Survivors/Dandelions

We have chosen the terms **Lifetime Survivors** and **Dandelions** to reference the community of people who have contracted HIV between birth and the first few years of life. We are Long Term Survivors, young (ish), and aging with HIV all at once.

Our bones and former meds lists share similarities with fellow Long Term Survivors, but the funerals we went to were often of our parents and siblings, our disclosures were not ours alone- they were a multigenerational family matter. The minimum enrollment age for studies leaves us behind and we are too treatment experienced or living with too many co existing conditions to enroll in the studies aimed at our age bracket.

Terms like Perinatal or Vertical can not only put stigma or blame on our birth parents, but also reduces us to our seroconversion. We would much rather come from a strengths based mindset.

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Dandelions

We also choose to think of ourselves as Dandelions, from that place of strength and in tribute to Mary Bowman's poem of the same name. Mary wrote that Dandelions "live in this matrix of life, understanding the price". For those of us who have lived a life of perpetually borrowed time with such a delicate balance of life, wellness, and illness, there is no more concise way to articulate the journey.

Most of us contracted HIV from our birth parents, but not all. We range in age from newborns to nearly 50 years of age. We were diagnosed between newborn and our late teens, and were told of our diagnoses in similar time ranges.

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Generations and Cohorts

Within our community we recognize that there are distinct generations/cohorts that shape our experiences as well as medical care and needs, often defined by birth year.

For example, those of us born before effective medications have very different canon events than those of us born into a world of the medications available in even the early 2000s.

A number of us are elite controllers or born outside the US and find ourselves floating between cohorts, or in another entirely distinct generation.