

## The Organization

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## Our Mission

- ◆ Assist in the search for HIV Controllers
- ◆ Link eligible candidates to clinical studies
- ◆ Mitigate barriers to study participation
- ◆ Foster community among HIV Controllers
- ◆ Maintain the HIV Controller topic in the public view

## Disclaimer

The information contained herein is designed to promote the understanding of Long-Term Non-Progressors (LTNPs) of HIV infection/HIV Controllers and is not intended to provide medical advice or to indicate eligibility for research studies. All persons with HIV or symptoms of HIV should consult a medical practitioner for diagnosis and treatment of HIV as well as any study eligibility.



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### Brochure Design

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## HIV Controllers

HIV Controllers, also known as “Long-Term Non-Progressors” (LTNPs), are divided into two categories. (Specific definitions may vary by study.)

### Viremic Controllers (VCs)

HIV+ individuals who

- register an HIV/RNA Viral Load (VL) at or below 2000 copies/mL;
- remain healthy with minimal rates of decline of CD-4 cells over time; and
- may have a history of anti-retroviral medications yet exhibit suppression of HIV despite lack of current treatment.

### Elite Controllers (ECs)

HIV+ individuals who

- register an HIV/RNA Viral Load too low to be detected (undetectable) by standard assays, sometimes indefinitely; or
- consistently register an HIV/RNA Viral Load below 50-75 copies;
- remain healthy with minimal rates of decline of CD-4 cells over time; and
- has never been on anti-retroviral medications (treatment naïve).

## Why are HIV Controllers important?

For more than 15 years, it has been apparent that a small minority of HIV+ people remain healthy despite years of infection. These individuals, estimated at 1 out of every 300 HIV+ people worldwide, sustain some level of infection yet show little evidence of clinical illness.

Due to their natural control of the virus, HIV Controllers are of extreme interest to scientists whose primary goal is to understand the genetic and immunologic factors that may contribute to their natural suppression of HIV without aid of medication. These individuals can contribute valuable information toward discoveries that can lead to the design of a therapeutic or preventative vaccine for HIV.

Identifying additional study participants is critical to understanding the phenomena of natural HIV control.

## General Statistics on HIV Controllers

Average age of study participant	<b>45.5 years</b>
Average duration of infection	<b>13 years</b>
Averages by gender	<b>26% female, 73% male</b>
Demographics	<b>86% U.S., 13% Europe, 1% Other</b>

## What's Next?

### For HIV Controllers

- ◆ Enroll in a clinical research study
- ◆ Share your story—write to us!
- ◆ Stay informed—visit our website.
- ◆ Educate others about HIV Controllers

### For Medical Professionals

- ◆ Visit our website for informative links to research entities and research abstracts.
- ◆ Inform eligible patients about research studies.
- ◆ Share information on HIV Controllers with colleagues.

### For Other Interested Parties

- ◆ Join us in identifying HIV Controllers.
- ◆ Learn more on our website!
- ◆ Help us fund our work by sending us a donation!

## The Zephyr Website

The Zephyr Foundation website provides links to studies of HIV Controllers, a comprehensive glossary of definitions, previously published interviews with HIV Controllers and research professionals, articles by and about HIV Controllers, and scientific abstracts on HIV Controller research finding.

We intend for the site to become a social outlet for the HIV Controller community via an online forum for registered members and will offer full scientific conference links.