# Life after HIV and beyond



#### **ADAM CASTILLEJO**

# THE LONDON PATIENT



# Who is Adam?

A British-Venezuelan man who lives in London who has a positive attitude to life despite all the obstacles.

Passionate about food and travelling, as a trained chef always wanting to explore new cultures and people.

Now as a a Motivational Speaker I am doing my best to inspire my HIV community around the world.

#### **Medical Background**

- Diagnosed HIV+ve 2003 in London
- Commenced on ART several years later
- Diagnosed with Stage IV Non-Hodgkin's Lymphoma (NHL) in 2012
- Several courses of treatment
- Told that no further possible treatment
- Researched further options and contacted a specialist at another hospital who agreed to take on care
- Bone Marrow Transplants successful BMT in 2016 from a donor carrying CCR5 Delta 32 mutation
- Doctors used experience gained from curing Timothy, The Berlin Patient.
- Stopped ART September 2017
- Declared first as *functionally* cure, later *operationally* cured now fully cured.



# Challenges

- Lifelong surveillance/regular medical checks.
- Affect on Mental Health. Stopping ART
- Complications from cancer treatment.
- Risk of cancer relapse and/or secondary cancers.
- Understanding the negative reactions from some long term survivors of HIV (to possibility of being cured).
- Educating people that the way I was cured is proof of concept and a blueprint for feasible cure in the future.
- No clear pathway for HIV Cure patients.
- Clinicians need to remember humans, not lab samples or case studies.

#### Legacy of Timothy Ray Brown



As our Cure Family continues to grow we must prepare for the next generation of cured people for the reality of life after HIV.

Before his death Timothy passed on the torch to me to continue the carry the message of hope and to lead my brothers and sisters -

- The Dusseldorf Patient
- The New York Patient
- The City of Hope Patient
- The Geneva Patient

# **Opportunities/Now:**

- New life/new start.
- Building platform as 'Ambassador of Hope' sharing with people living with HIV that cure has been proven as possible. (Proof of Concept).
- Motivating scientists and researchers to persist with their endeavours to find a workable cure.
- Helping raise funds for HIV Cure research.
- Connecting people around the world.
- Head of 'Cure Family'.



# **Conclusion/The Future**

- The aspiration for The London Patient project is to create a charity which would aim to focus on HIV Cure.
- Bridge the gap to existing organisations whose focus is solely on prevention, or treatment.
- Be a hub to connect communities around the world
- Continue travelling as Ambassador of Hope to deliver message of resilience and hope