

# Towards a Cure

100,000

Infected with the HIV virus in the UK



Working Together to Cure HIV

The background of the slide features a light blue, textured surface with several large, stylized, white-outlined structures that resemble viruses or microscopic organisms. One prominent structure in the upper right is spherical with many small, rounded protrusions. Another in the lower left is more elongated and has many thin, rod-like protrusions. A third, smaller spherical structure is visible in the lower right.

## **Key Statistics**

- **35 million people have HIV worldwide**
- **100,000 infected with the HIV virus in the UK**
  - **20,000 deaths from HIV in the UK so far**
    - **6000+ new infections each year**
- **of all new HIV infections in the UK most are acquired at home and not abroad**
  - **a quarter of people infected with HIV in the UK don't realise they have it**

# Foreword

**“We have made extraordinary progress since I mounted the “Don’t Die of Ignorance” campaign on AIDS in 1986. Thanks to the progress made in treatment since then millions of lives have been saved. The challenge is to take that progress further. The science required to develop this needs funding in order for it to succeed. BHIVA as the National Association representing doctors and others who care for HIV patients in the UK is ideally placed to ensure the funding for this is directed to where it will make the greatest difference.”**

**Lord Fowler, Patron, BHIVA**

## Message

**“Our priority should be to find a cure for HIV. It is our duty. Even though there is a long way to go we have to start somewhere. If we don’t make a start then we will never see success.”**

**Professor Françoise Barré-Sinoussi, awarded the Nobel Prize for medicine in 2008 for her work in the 1980s on the discovery of HIV, the cause of AIDS.**

**Honorary life member of BHIVA**

# The Problem

The past 30 years have seen the emergence of an HIV epidemic which has killed 20,000 people so far in the UK. There are now 100,000 people living in the UK with HIV and despite intensive scientific research no effective vaccine has yet been developed to prevent infection or to treat infected patients. Due to the devastating scale and impact, the global HIV epidemic is still one of the most formidable challenges to human life and dignity. Separately but significantly HIV undermines social and economic development throughout the world, affecting all levels of society: national, community, family and the individual.

## Treatment Yes - Cure No

One of the most impressive achievements of the last century must be the discovery of HIV in the 1980s and the development of effective medical HIV treatments. This once universally fatal disease is now treatable with a combination of new drugs. But still there is no cure. HIV drugs must be taken for life and they bring with them a whole range of associated problems. The drugs can have severe side effects and resistance to the drugs may develop over time. As yet the effect of these powerful drugs is only just beginning to be understood. HIV patients not only experience side effects from their therapy but also find it difficult to come to terms with their diagnosis; they are reminded of this several times each day as they take their medication. Other HIV patients are so worried by the stigma surrounding HIV that they are too afraid to have an HIV test or to attend local hospitals. In some cases patients don't take their medication in case they are discovered. **Imagine being too afraid to take treatment which could save your life.**

**HIV has a real and tangible cost to society. Each year the progress made in treatment offers increased life expectancy, but with the combination of ongoing new infections and rising drug costs this means that Health Service budgets are rising exponentially. In the UK alone the cost to the NHS to provide antiretroviral therapy for those living with HIV is an estimated **£1 billion annually**. These rising costs are not sustainable in the medium or long term.**

**The only real answer is A CURE**

## The Doctor

When will I die?

When will there be any treatment?

These were the questions asked by my patients in the 80s. That was then, now they ask:

When will there be a cure?

You may think that now with effective treatment we should just be happy that people aren't dying - but they still are. Having HIV remains a stigmatised condition. My patients are still ostracised by work colleagues and hide their medication from family, friends and co-workers. Many young people infected at birth don't dare have a relationship for fear of disclosing their status or transmitting to others. Others are experiencing complications due to the treatment: kidney disease, bone-thinning, the list of problems goes on. I like looking after my patients, but I would like it better if they never had to see me again - that their time was spent without doctors' visits, and that pregnant women didn't have to take tablets to prevent them passing the virus on to their babies.

I used to say we need more research to find treatments - now I say we need a cure

**Dr Karen Rogstad**

## The Patient's Story

Next year, I'll have had HIV for half my life. I've learned to deal with it. The pills I take daily keep me as healthy as the average 56-year old; confronting mortality has given me a lot of resilience and it's put me in touch with a global network of astounding people. A cure wouldn't replace the decade I spent waiting to die or the entire generation of friends it wiped out, but I'd be first in line for a viable procedure that gets it out of me. Not because I think HIV will kill me, but because of the ever-increasing stigma and ignorance that surrounds it. I have learned to deal with sexual rejection, to wearily teach the people who still insist it's as contagious as flu, and to defy the assumptions people make about me. Yet if I delve deep, it still feels like an unjust life sentence; in the prophetic words of novelist **Philip K Dick** in 1977, people with HIV were "*punished entirely too much for what they did*". He was talking about drug addiction, but it's the same thing: [a life marked apart for a few youthful indiscretions, or just for having sex at all](#). And if I feel that way, what of the young people who are catching it now? So, much as I'd be entirely proud to die still HIV-positive, I would jump at the chance to die HIV-negative, having survived the worst it could throw at me and in the end, vanquishing this virus.

**Gus Cairns**

## Living With HIV: It Isn't Good Enough

Although antiretroviral therapy (ART) has the ability to control the new production of HIV, it can only block the virus growing for the time the individual is regularly taking treatment. This is because the virus can infect resting cells, which are invisible to the immune system as well as the drugs. If ART is stopped then the resting cells start dividing and new virus particles are made and the virus comes back. Despite years of successful treatment, removal of the virus 'hiding' in these resting sites has not been possible and so a cure for HIV has not been achieved. Although ART has dramatically improved the survival of people living with HIV there is always a continued risk of onward viral transmission. Whilst ART is effective at reducing this chance it requires **lifelong adherence, which is extremely challenging** for many.

### Diary entry of an HIV Patient

*Another day, another round of routine testing and then off out tonight, it's my partner's birthday really looking forward to meeting all our friends.*

*Later...*

*It's bad news, the tests show my treatment might not be working. The doctors are not sure what this means, is the virus really back, have I got resistance? Will my pills still work? If they don't then what next?*

BHIVA has been awarding small grants to fund HIV research since 2008.

## Sarah Watters

In 2012 Sarah gained a BHIVA Research Award to develop novel laboratory tests to help measure HIV in various parts of the body where HIV can lie dormant. The aim of the research was to develop highly sensitive laboratory tests that can be used for the detection of HIV replication. These findings will be used in studies aiming to provide a deeper understanding of what happens to the virus when it lies dormant in so called sanctuary sites or 'reservoirs' in the body, and also to more accurately measure how this is affected by various drug treatments. This research will be essential for monitoring the effectiveness of new treatments designed to clear these difficult to reach parts of the body where the virus has been able to remain dormant. This can potentially lead to a cure.

### **Sarah Watters is a Clinical Scientist working at University College London Hospital**

*Sarah's crucial work has been supported by a BHIVA Research Award. Funding was also received from the Wellcome Trust and the work is being undertaken in collaboration with University College London (UCL) and the National Institute for Health (NIH) in Maryland USA. This is a good example of the collaborative work BHIVA aspires to fund in the future.*



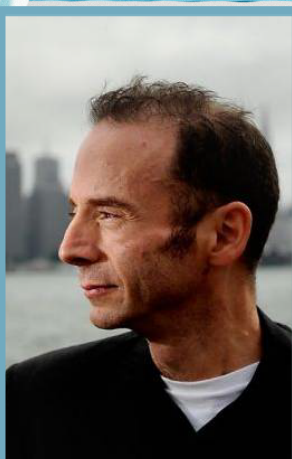
# Why BHIVA? Why NOW?

Finding a cure for HIV must not, and is not, considered impossible. In the UK we are in a strong position to lead in the pursuit of a cure.

The UK has a strong research background in the field of HIV and clinical research with an excellent record of collaboration across the UK and internationally.

An extensive and ambitious research programme must be developed to better understand the basic science of HIV and avenues of research that are being pursued by drug companies and by other research institutions. The doctors, who treat and look after the patients, understand the need more than anyone. Our first hand knowledge and our positions give us the unique experience and insight to co-ordinate this collaboration of UK researchers that can effectively turn the basic science and research into patient-led studies.

**Each study takes us one step closer to finding a cure.**





An iceberg floating in the ocean, with the tip above the water and a much larger mass submerged below. The image is used as a metaphor for HIV, where the visible tip represents the known aspects of the virus and the submerged part represents the hidden challenges and the need for a cure.

# 1980s

- AIDS cases diagnosed
- discovery of HIV
- HIV prevention campaign launched
- HIV Ab test (tests to measure damage to the immune system caused by HIV)
- anti HIV drugs

# 1990s

- effective mother to child transmission prevention
- combination treatments
- tests to monitor treatment success
- sequencing of HIV to predict which drugs will work best

# 2000s

- single tablet combination treatments
- new classes of drugs enabling almost all HIV patients to be treated effectively, including those with drug resistance
- Timothy Brown becomes the first patient cured of HIV

**Now is the time to find a cure for HIV  
- it's in all our interests**

## **Timothy Brown “The Berlin Patient”**

Timothy Brown had the misfortune to be diagnosed with Leukaemia as well as HIV. As part of his treatment for Leukaemia he underwent total body irradiation, had a bone marrow transplant and had a variety of anti-cancer drugs as well as his HIV treatment. **He was fortunate to survive this treatment.**

The doctors caring for him chose a bone marrow donor who was one of the tiny minority of people who have some natural immunity to HIV in the hope that this would help Timothy fight off HIV.

**Timothy has been off HIV treatment for three years with no sign of the virus returning.**



# The Solution - Towards a Cure

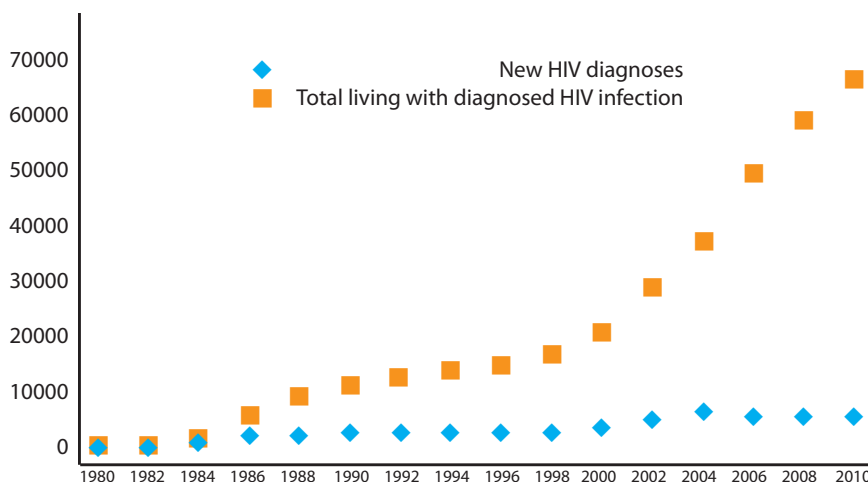
Reduction of the viral reservoir is likely to require two interventions to ‘**shock**’ and then ‘**kill**’ the cells that are otherwise infected but not recognised as such by current therapy or the immune system. These are:

- the re-activation of HIV from latently infected cells
- The elimination of these re-activated cells

It is estimated that for people living with HIV and taking successful antiretroviral treatment, the number of resting white blood cells harbouring the virus is one in a million. In order to find these cells they must be ‘lit up’ to find the virus inside them. We can then either block the virus ever being produced or kill these cells.

Strategies currently under investigation by researchers globally include:

- The re-activation of HIV from latently infected cells
- The use of treatments that activate the resting cells
- Gene therapy which can remove or switch off the virus ‘hiding’ within these resting cells
- Vaccines that strengthen the immune system to recognise these resting infected cells
- A combination of the above approaches



Proof of concept studies are currently underway testing these strategies. For the very first time there is new hope in the field of HIV following the report of the first ever case of an individual with proven HIV being cured.

But it is only with support from the researchers, funders and community that a real difference can be achieved.

## Finding the virus

BHIVA would like to fund research projects in this vitally important area. HIV hides, it finds places in the body that HIV drugs cannot reach. We need to fund research into this area so that we then know where to target treatment. If we are to give those who already have HIV the release they need, it is vital that we undertake this research.

## Measurement of viral latent reservoirs

It may be possible to either eradicate the virus from resting cells with novel drugs or a combination of drugs, or to flush the virus out of these cells by using cancer drugs. In order to evaluate these strategies we need to be able to measure the amount of virus present in very tiny quantities and determine whether the virus we have found is still alive to see if these methods are effective.

## Using drugs to flush out the virus from cells where it remains dormant

Currently the available treatments which do this are the kind of toxic drugs used to treat cancer. We need to study the effects of these drugs when used to treat people with HIV who also need them for treatment of their cancer. These studies will show us if this will be a way to attack the virus. This may have been one of the reasons Timothy Brown was cured.

## Gene therapy

One of the other reasons Timothy Brown was cured was that he underwent a bone marrow transplant with cells which lacked the receptor for HIV. This is clearly too dangerous and expensive to be used routinely in patients; however, there may be other ways of achieving the same result. This might be through inserting the gene found in people with some natural immunity by using a modified virus or by vaccination. These strategies show us what might be possible. As with Timothy Brown, a combination of these approaches might be required. The challenge is to find a strategy that ultimately is cheap, scalable, widely available and ethically acceptable to our patients.

## Social research

HIV is unique in its social dynamic: infection attracts stigma, prejudice and fear. Even in the UK in 2013, all of these factors hamper prevention efforts, access to HIV testing and ongoing treatment. Recent research sponsored by BHIVA highlighted the impact of gender based violence on the uptake of treatment and its long term effectiveness. We need further work in this area and areas like this to find the most effective strategies to ensure that any advances in medicine and science can reach the people who need them.

## Angelina's Story

For me, a cure would mean that I wouldn't only be freed from the medication, but from the social stigma as well. I had just left university when I was diagnosed - a time when I felt like I had a bright future ahead of me. When I was growing up I wanted a stable life, a family, and for me that meant finding a stable relationship as well. But when you're living with HIV, starting a relationship is not so easy. You always have to think about disclosure. Letting someone know that you're living with HIV is a very personal and very intimate thing. Even if you like someone straight away, you always have your HIV status at the back of your mind. It has taken me a long time to have a conversation without having to think twice about what I say. There are still a lot of barriers out there. You can't just have a conversation about HIV with people. Unlike some long-term illnesses, after you've been diagnosed with HIV the last thing that people want to do is to rally around you. When you have HIV, you take a pill and you remember what you are living with. We have made great advances in developing drugs to prevent transmission, and we need to acknowledge that treatments are very effective in keeping people alive. But even though I appreciate that this medication is keeping me alive, I also know that there are 7 million people globally living without access to HIV medication. We can never lose sight of those who need treatment now. A cure would inevitably impact on everybody, and the global impact of a cure would be enormous. We have come an extremely long way, and to some extent attitudes have changed due to the number of people who are affected around the globe, but so many people are still dramatically affected through violence or are being ostracised - only a cure would permanently put an end to this.

**Angelina Namiba (Positively UK)**

*Interview (edited conversation)*

*As I lay there in the coronary care unit attached to drips and beeping monitors I tried to take in what I had just been told, I'd had a heart attack. This was the last thing I imagined would happen to me as I already had HIV and that was enough bad luck for anyone.*

### Background

Patients living with HIV in the UK are unlikely to die of AIDS but HIV seems to age the body faster.

Illnesses associated with later life such as heart, bone, liver, and kidney disease are a major problem.



# The Need for £1 Million

## Finding a Cure for HIV

BHIVA needs £1 million to launch a sustainable initiative to change the lives of the 100,000 men, women and children in the UK living with HIV. BHIVA believes that such a sum invested in the right research will make a significant and important contribution to finding a cure for this virus.

Small research projects are vitally important as they often lead the way to the crucial breakthrough and provide the science on which larger research programmes rest.

BHIVA are proud to be leading this great venture. By taking all of the evidence gathered over the last 30 years and all of the experience of our members working to care for those with the virus, we believe we can deliver a cure.

BHIVA believes that by spear-heading this far-reaching strategy that takes all of the science, all of the knowledge, and all of the experience we will find a cure for HIV.

**The funds raised will be used to make this happen.**

## Costs

BHIVA wishes to fund small projects which would not attract funding from traditional sources as well as work with partners to support larger projects.

For example a recent small trial of 35 patients cost almost £1.5 million

- **Clinical costs £330K**
- **Trial management £350K**
  - **Research £750K**



# How You Can Help

Message from Professor Jane Anderson,

Chair of BHIVA 2011-2013

BHIVA is a multidisciplinary association whose members have responsibility for the care and treatment of people living with HIV in the UK.



We are ideally positioned to ensure that the funds raised will not only go to funding basic scientific research for a cure but also on research to ensure advances in science are effectively delivered to those who would see the greatest benefits.

The effective translation of advances in medicine into the clinical delivery of care is an area where physicians in the UK have an excellent record with some of the best outcomes in the world.

Your support, whether as an individual, as a business, or a trust or foundation is vital to sustain the drive to achieve a cure for HIV.

With your support we can go on to fund the research which is vital for the millions of men, women, and children who have contracted HIV and will continue to do so.

The future is in our hands. We can take action now, today, or we can wait until we are forced to take action when the inevitable economics of treating the virus are beyond the scope of governments throughout the world, **when those living with the virus are viewed as economically unviable.**

A CURE FOR HIV - it's in all of our interests.

Please help, we need your support to raise £1 million to fund this extensive and far-reaching research programme.

**One more death is one death too many....**



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