What will happen while you are on treatment for Chagas disease?
You will need to have a follow-up appointment and a blood test 1 week after starting treatment with benznidazole, and then every 2 weeks until you have finished the course.

What should you do if you suffer side effects while you are taking benznidazole?
If you experience any side effects while you are taking benznidazole, or if you have any questions about your treatment, you should contact us at:

**The Hospital for Tropical Diseases**
0203 456 7891 / 0203 447 5990
Monday to Friday, 9am – 5pm.

It is helpful if you have your personal record number (MRN) and the name of the doctor who saw you in your last appointment. You can find this information on the letter you will have received from the HTD. You will be assessed on the telephone and you may be asked to come into the clinic for an assessment.

If you have any problems outside working hours that require urgent medical attention, you should go to your nearest emergency medical service.

You should always mention that you are taking benznidazole to other doctors or pharmacists before taking any other medications.

How effective is the treatment?
Drug treatment for Chagas Disease is most effective in children and soon after infection occurs (around 100% success). Treatment is less effective at clearing the parasite when the infection has been present for many years, and a second course of treatment may occasionally be needed. In addition, there remains some uncertainty about how effective clearance of the parasite is at preventing future development of the gut or heart complications of Chagas disease, and your doctor will discuss this with you. In advanced heart or gut disease there is unlikely to be much benefit from benznidazole treatment as most damage is not reversible. However symptoms of heart or gut problems can be managed by conventional treatments.

To know whether treatment has been effective, you will stay under the care of the Chagas Clinic for annual appointments, ECGs and blood tests.

**Contact us:**
email: ukchagashub@lshtm.ac.uk
twitter: @ChagasHubUK
facebook: UK Chagas Hub

**The Hospital for Tropical Diseases**
Mortimer Market Centre, Mortimer Market, Capper St, Fitzrovia, London WC1E 6JB
0203 456 7891 / 0203 447 5990
Monday to Friday, 9am – 5pm.

Thank you for taking the time to read this leaflet.
What is Chagas disease?

Chagas disease is caused by infection with a parasite called Trypanosoma cruzi. It affects around 7 million people worldwide. The parasite is found throughout Central and South America and the disease affects people from these countries, particularly those who live or have lived in rural areas. Rates are highest in Bolivia where up to 70% of people are affected in some areas.

The insect that spreads the disease is not found outside Latin America. However, once a person has the infection they remain infected for decades, often with no signs or symptoms of illness. As there are now large numbers of people who were born or grew up in Latin America and who are now living in other countries around the world, there are many people with Chagas disease who may be unaware of their infection.

London has a large Latin American population. The total number of people with Chagas disease in London is not known, but it is thought that there may several thousand. Most of these people do not realise that they are at risk and so might never have been tested.

How do people catch Chagas disease?

In Latin America Chagas disease is spread by insects called triatomine bugs (also known locally as ‘vinchuca’ or ‘chirimacha’). They live in cracks in walls and in thatched roofs and usually bite at night. Less commonly, Chagas disease can be spread by drinking contaminated fruit juice, or by blood transfusion or organ transplantation. In a small proportion of pregnancies the parasite can be passed to the baby by infected mothers. This is called congenital infection.

What are the symptoms?

Immediately after becoming infected, a small number of people experience a mild illness with fever which gets better by itself. Most people have no symptoms at all and so do not know that they are infected.

The infection can then remain silent and for most people this causes no illness during their lifetime. However, one in three people can develop problems – with either their heart or their digestive system or both - after years or decades, and this is why detection and treatment of infection is important. The heart rhythm and heart pump strength might be affected so symptoms can include breathlessness, ankle swelling, dizziness or collapse. Problems with the digestion such as difficulty swallowing or constipation can also occur.

When is treatment recommended?

- People with chronic infection (before symptoms develop) or with mild or moderate symptoms
- Congenital infection (infection acquired by the baby during pregnancy)
- Reactivation during immunosuppression.

Who will treat your infection?

Treatment for Chagas Disease should be managed by doctors in a specialist centre, such as the Hospital for Tropical Diseases (HTD), which has experience treating patients with Chagas disease.

How is Chagas disease treated?

The two drugs available to treat Chagas disease are benznidazole and nifurtimox. In the UK we use benznidazole for 60 days.

After your initial assessment at HTD the doctor will discuss the benefits and drawbacks of treatment and, if you decide to take treatment, will prescribe the correct dose of benznidazole for you and provide you with information on what to expect during treatment. The drug has to be requested from overseas and may take 2-4 weeks before it is available. You should bring the medication to your next appointment – after a blood test at that appointment you should start the medication. You will be reviewed frequently during the first few weeks to help you deal with any side-effects. Though side-effects are common they are mostly mild and reversible (they disappear by themselves or after the medicine has been stopped). They can also normally be managed with medication.

Mild side effects include:
- Rash (up to 50% of patients)
- Nausea or vomiting (15%)
- Headache, tiredness, or sleep difficulties (40%)

Rarely, serious side effects might include:
- Nerve inflammation
- Blood abnormalities (anaemia or low white blood cell count).