ANTIPHOSPHOLIPID SYNDROME FACT SHEET

- APS Support UK is the only UK registered charity dedicated to raising awareness and funding research into antiphospholipid syndrome (APS). Its prime objective is to educate both the medical profession and the general public about a seriously under-diagnosed condition. Our mission is to save and improve lives of people with APS by achieving earlier diagnosis and improved treatment through education, information, support, and research. aps-support.org.uk
- Antiphospholipid syndrome (APS), sometimes known as Hughes syndrome and, more colloquially, 'sticky blood', is an autoimmune disease in which there is an increased tendency for the blood to clot too quickly both in veins and arteries. It can affect any organ of the body giving rise to potentially fatal events such as heart attacks, strokes and DVT. Early diagnosis and appropriate treatment can often prevent these serious complications developing and reoccurring.
- APS can be detected with three relatively simple blood tests: aCL
 (anticardiolipin), LA (lupus anticoagulant) and a newer test: anti-beta2glycoprotein1. The blood tests are inexpensive costing approximately £70 on
 the NHS, and are available at most laboratories throughout the UK.
- Once diagnosed, treatment can be as simple as a low-dose aspirin or bloodthinning drugs such as warfarin and heparin.
- The disorder affects all age groups from infancy to old age, but the majority of patients are diagnosed when they are aged between 15 and 50. It is more common in women than in men – for every two men with APS, there are seven women affected, although this may be because of its more well known effect on pregnancy.
- APS is responsible for 1 in 6 of all strokes heart attacks and DVTs in people under 50, and is recognised as the most common, treatable form of recurrent miscarriage.
- In pregnancy APS can cause early or late miscarriage and women are five times more likely to suffer a stillbirth if they have the condition. It is the most common treatable cause of recurrent miscarriage, and the recognition and treatment of APS improves the chances of preventing miscarriage from below 20% to 70%-80%. At present women are not tested for APS until after three consecutive miscarriages.

- Although still thought of as rare, the UK estimate of people at risk from APS
 1% of the population more than suffer from Parkinson's disease or multiple
 sclerosis. Studies in the US indicate that it could be as high as 2-4%, but no
 wide-scale prevalence study has yet been carried out.
- A study published in *Clinical Rheumatology* 2009 found that the average time for a patient with APS to be diagnosed is three years it is often many more.
- APS was first described in 1983 by a London team of doctors led by Professor Graham Hughes (<u>British Medical Journal 1983, 287, pp.1088-1089</u>).