



## Media Release

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### **Cycling a PHenomenal ride to raise awareness of the rare disease pulmonary hypertension this UK PH Awareness Week**

**CHISWICK, LONDON – 22 October 2018:** during UK PH Awareness Week (22 – 28 October 2018) a team of inspirational cyclists representing Team PHenomenal Hope UK and Ireland will ride a challenging 200+ miles over three days to raise awareness of the life-limiting rare disease, pulmonary hypertension (PH). This exciting event is jointly supported by the charities Pulmonary Hypertension Association UK (PHA UK) and Pulmonary Hypertension Association Ireland (PHA Ireland) and is organised and funded by Actelion UK.

PH is a serious condition, which affects over 7,000 people in the UK.<sup>1</sup> It is high blood pressure in the blood vessels that supply the lungs (pulmonary arteries), which can damage the right side of the heart. This can lead to heart failure, which can be fatal. One of the challenges with PH is that the symptoms, which include breathlessness, tiredness, feeling faint or dizzy and swelling in the legs, ankles, feet or stomach area, are often misdiagnosed for other, less severe conditions.<sup>2</sup> Therefore PH can remain undiagnosed for years, having a detrimental impact on patient prognosis and quality of life.

The nine core riders of Team PHenomenal Hope UK and Ireland, who are riding to raise PH awareness, will complete all three days of the tour (23 -26 October) and will be joined by a mix of day riders along the way. The core team comprises healthcare professionals from PH specialist centres in the UK and Ireland, representatives from the two patient advocacy groups PHA UK, PHA Ireland and staff from Actelion UK and Ireland.

Iain Armstrong, Chair, PHA UK says, “UK PH Awareness Week aims to put PH firmly under the national spotlight through a week of concentrated activity. This year we are working on a number of initiatives to support the PH community and are delighted to support Team PHenomenal Hope’s endeavours with a ‘send-off’ event at our offices in Sheffield. PH is a devastating disease and I encourage anyone affected to visit our website [www.phauk.org](http://www.phauk.org) to find out what resources and support are available to you”.

The route will start at the PHA UK offices in Sheffield, with a stop at the PH specialist centre, Royal Papworth Hospital in Cambridgeshire and finishing at Imperial College London, which has research links to both the Hammersmith Hospital and Royal Brompton Hospital (both PH specialist centres), where a closing event will be held. Along the route, a series of inspirational and educational awareness events will be held for those impacted by PH, including patients and their friends and families.

Professor Sean Gaine is the PHA Ireland representative and lead PH specialist at the Mater Misericordiae University Hospital Dublin and a member of the core Team PHenomenal Hope UK and Ireland cycling team. He comments: “This cycle ride is a great opportunity to join



forces with colleagues and friends in the UK to raise awareness about PH. Cycling from the head office of PHA UK in Sheffield to London while meeting with patients and families along the way is a very special way to raise that awareness. For people living with PH, this endurance cycle would be impossible. PH can't be cured, but early diagnosis and treatment can improve prognosis and quality of life, which is why raising awareness of the disease is so important."

Fellow cyclist and General Manager of Actelion UK and Ireland, Robin Bhattacharjee explains why Actelion is organising this event: "By working with the wider PH community through an event like the Team PHeNomenal Hope ride during UK PH Awareness Week, our aim is to raise awareness of this devastating, rare and life-limiting disease. As an organisation we are committed to addressing the unmet needs of people with PH and this means where possible reducing the time to diagnosis and ensuring access to the full range of available therapies. I am sure the riding part of this challenge will be hard, but not half as hard as living each day with PH; I know this will motivate me and my fellow cyclists when the going gets tough and I feel privileged to be part of the group".

For more information on PH, Team PHeNomenal Hope UK and Ireland and the tour please visit: <http://bit.ly/Facebook-TeamPHeNomenalHopeUKIreland>; [www.phauk.org](http://www.phauk.org); <https://www.pulmonaryhypertension.ie/pha-ireland>

To support the team and the event on social media, please use the hashtag:  
**#TeamPHeNomenalHopeUKIreland**

**# ENDS #**

## NOTES TO EDITOR

### BACKGROUND TO PH: [www.phauk.org](http://www.phauk.org)

- PH is a serious condition where the blood pressure in the pulmonary arteries is high. This causes progressive damage to the heart and lungs.
- The main symptom of PH is breathlessness, however, other symptoms may include dizziness, feeling faint, swelling of the feet or ankles, and chest pain (particularly during exercise)
- There is no cure for PH, however, there are several different treatments available.

### ABOUT PHA UK: [www.phauk.org](http://www.phauk.org)

- The Pulmonary Hypertension Association UK (PHA UK) is the only charity in the UK dedicated to people with the rare disease, pulmonary hypertension (PH).
- Set up in 2000, PHA UK has grown to a membership of almost 4,000 – a unique group of people committed to supporting each other and raising awareness of this serious condition in the hope of one day, finding a cure.

### ABOUT PHA IRELAND: <https://www.pulmonaryhypertension.ie/pha-ireland>

- PHA Ireland was established in 2005 as a registered charity and patient support organization raising the profile of PH and providing help and information for people who are diagnosed and living with this disease in Ireland.

### ABOUT ACTELION PHARMACEUTICALS LIMITED: [www.actelion.com](http://www.actelion.com)

- Actelion is a leader in the field of pulmonary arterial hypertension (PAH), a type of PH. Our portfolio of PAH treatments covers the entire spectrum of care, from WHO Functional Class (FC) II through to FC IV, with oral, inhaled and intravenous medications.
- In June 2017, Actelion became part of the Janssen Pharmaceutical Companies of Johnson & Johnson. Actelion's medicines help expand and strengthen Janssen's portfolio with leading, differentiated in-market medicines and promising late-stage compounds. Janssen's mission is to



transform individual lives and fundamentally change the way diseases are managed, interpreted, and prevented. Janssen has been accomplishing this through a focus on five important therapeutic areas: cardiovascular and metabolism, immunology, infectious diseases and vaccines, neuroscience and oncology. Janssen is establishing pulmonary hypertension (PH) as its sixth therapeutic area of focus to maintain the leadership position Actelion has built in this important disease area.

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