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Immunocore and Pulse Infoframe, Inc. Partner with Leading Academic Institutions to Launch First Global Patient Registry for Uveal Melanoma

July 18, 2019

Patient-reported data will help inform research in rare form of eye cancer

(Oxfordshire, UK, Pennsylvania and Maryland, US and Ontario, CA, 18 July 2019) Immunocore Limited, a leading T cell receptor biotechnology company, and Pulse Infoframe, Inc. (Pulse), a data aggregation and analytics company, today announce plans to support the first global patient registry in uveal melanoma (UM), a rare and aggressive form of melanoma, which affects the eye, typically has a poor prognosis and for which there is no currently accepted optimal management or treatment.^[1] The insights gained through the academic registry will provide a more comprehensive understanding of the disease and may help to shape the way future research is conducted.

Richard Carvajal, together with collaborators Joseph Sacco and Anthony Joshua, began the initiative in 2016 as a resource for academic medical centres and industry partners and a way to accelerate the drug approval process for this rare disease.

"The rarity of uveal melanoma makes it difficult to collect the data needed to better understand how the disease manifests and evolves, and who is likely to respond to treatment and why," **said Dr. Carvajal**. "For the first time we'll have the opportunity to prospectively collect and analyse global real-world data, including patient-reported outcomes. This will help to guide medical research, innovative trial design and recruitment, potentially paving the way for accelerated treatment advances."

The registry will include institutions from across the US, UK and Australia, and is currently being developed by leaders in the field of uveal melanoma, including:

- Richard Carvajal, MD, Associate Professor of Medicine at Columbia University Vagelos College of Physicians and Surgeons, Columbia University, US
- Joseph Sacco, FRCP, PhD, Clinical Senior Lecturer at the University of Liverpool and Honorary Consultant in Medical Oncology at Clatterbridge Cancer Centre, UK
- Anthony Joshua, MBBS, PhD, Director of Medical Oncology, Kinghorn Cancer Centre, St Vincent's Hospital and conjoint Associate Professor with the University of New South Wales, Australia

Research generated from the registry will examine risk factors, genetics, epidemiology, treatment cost-effectiveness and real-world outcomes from a database of patients with uveal melanoma. The goal is to create a benchmark framework, or ecosystem, for collecting and assessing clinical outcomes, as well as providing necessary data for future genetic, sub-phenotype and biomarker research.

"We're excited to be working with the research community to address the need for a more comprehensive understanding of uveal melanoma," **said Mohammed Dar, MD, Head of Clinical Development and Chief Medical Officer at Immunocore**. "We believe that this registry will provide critical insight that may help to advance the development of future treatments, including clinical and genetic information about potential subsets of people living with this devastating disease."

Enrolment into the registry is expected to begin in August at five sites in the US, three sites in the UK, and three sites in Australia.

"At Pulse, we strive to support the entire ecosystem that researchers, clinicians and patients require to generate the real-world evidence necessary to advance clinical outcomes, support patient advocacy and promote disease awareness," **said Femida Gwadry-Sridhar, RPh, PhD, CEO and Founder at Pulse**. "We are pleased to partner with Immunocore and key academic leaders on this patient registry, which will provide a detailed look into uveal melanoma from a global perspective."

^[] Carvajal, RD, Schwartz, GK, Tezel, T, *et al.*, 2017. Metastatic disease from uveal melanoma: treatment options and future prospects. *British Journal of Ophthalmology*, 101(1), 38-44.