Sciensus and Rare Patient Voice present new data at ASCO on the access burden facing rare cancer patients in Europe

LONDON, UNITED KINGDOM, June 1, 2026 /EINPresswire.com/ -- Sciensus, a leading European life sciences organisation focused on accelerating patients' access to life-saving medicines, and Rare Patient Voice, a Konovo company, today announced the presentation of data at the 2026 ASCO Annual Meeting showing that people living with rare cancers may face a distinct and heavier treatment access burden than the wider cancer population in Europe.

The poster, Patient-Reported Barriers to Treatment Access and Home Delivery in Cancer Care Across Five European Countries, analyses cross-country survey responses from 134 people affected by cancer, including a rare cancer subgroup of 16 respondents, to examine treatment access, medication collection burden, home-delivery experience and lived experience across France, Germany, Italy, Spain and the UK.

This ASCO presentation focuses specifically on cancer patients and their caregivers and brings the rare cancer subgroup into sharper view. It shows that while access burden exists across cancer care more broadly, rare cancer respondents reported longer travel times, more fragmented pathways, lower visibility of specialist support and limited participation in Early Access Programmes (EAPs) or clinical trials.

Among all cancer respondents, 44% reported spending more than one hour collecting medication and 57% either lacked access to home delivery or were unaware of the option. At the same time, 90% said home delivery would improve quality of life, underlining the potential value of more flexible, patient-centred oncology delivery models.

For the rare cancer subgroup, the burden appeared even more acute. The poster reports that 62% spent more than one hour collecting medicines, 31% spent more than two hours and 19% spent more than four hours, compared with 44%, 17% and 7% respectively in the broader cancer cohort. Only 3 of 16 rare cancer respondents reported participation in an Early Access Programme or clinical trial.

“Rare cancers present unique challenges because patients are often required to navigate highly specialised and geographically dispersed services,” said Dr Sherif Raouf, Clinical Director, Cancer, Sciensus. “This analysis highlights the cumulative impact that fragmented access pathways can have across the treatment journey, demonstrating that these barriers are not peripheral to care,

but can directly shape how patients experience treatment. The findings reinforce the need for care models that minimise disruption throughout treatment and help patients remain more connected to clinical support during therapy."

Mark Hawken, Managing Director, Cancer Services at Sciensus, said: "As cancer services continue to evolve, there is increasing recognition that treatment delivery must be evaluated alongside clinical care itself. Analyses such as this help identify where practical barriers persist and where service redesign may improve continuity of care, reduce avoidable pressures on patients and support more efficient use of healthcare resources."

Pam Cusick, Senior Vice President, Rare Patient Voice said: "For people living with rare cancers, many of the greatest challenges happen outside the clinic. Patients and families are often navigating complex care journeys, long travel distances and uncertainty about where to find appropriate support or expertise. Research like this is important because it ensures patient experiences are not treated as secondary to clinical outcomes, but as essential insight that should help shape how future cancer services are designed, delivered and evaluated."

The study also identified recurring qualitative themes within this sample of rare cancer respondents, including travel to tertiary centres, difficulty accessing specialist expertise, financial strain, unclear care pathways, low awareness of EAPs or trials, and the need for more psychological support for both patients and families.

These findings have direct implications for cancer stakeholders focused on improving equity and continuity of care. The poster concludes that decentralised and hybrid treatment models, proactive EAP outreach, integrated care navigation and home-based delivery of treatment may help reduce the disproportionate logistical and financial burden experienced by rare cancer patients and caregivers.

About Sciensus
Sciensus is the UK's leading provider of complex clinical care at home. For over 30 years, we have partnered with the NHS to deliver specialist medicines, clinical nursing and patient support to people living with cancer, rare diseases and complex long-term conditions – supporting more than 300,000 patients a year across 180+ NHS trusts. Beyond the UK, Sciensus helps pharmaceutical and biotech companies reach patients across Europe, managing the regulatory, logistics and patient support complexity of launching medicines in multiple markets.

About Rare Patient Voice
Rare Patient Voice, a Konovo company, connects patients and family caregivers with research opportunities so their experiences can help improve medical products and services.

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