Patient groups, clinicians and industry challenge the status quo at rare diseases inquiry hearing

***Pharma News*: The Senate Community Affairs References Committee, chaired by Green's Senator Janet Rice, held a public hearing in Sydney yesterday, spearheading an Opposition-led inquiry into equitable access to diagnosis and treatment for individuals with rare and less common cancers.**

Addressing the committee, Associate Professor Christopher Steer, President of Private Cancer Physicians of Australia, emphasised "We need to end the cancer lottery where a patient with a particular diagnosis can get support for their treatment whereas another is denied … because their cancer is of the wrong type."

Expressing deep frustration at the lack of equitable and timely access to new diagnostic technologies and innovative therapies, Professor Steer highlighted the challenges faced by Australians with rare cancers.

"We will hear about the game changer that is genomics or precision medicine however we also know that if a test diagnoses a rare cancer, the likelihood of an available treatment is much less and the costs of these treatments are often prohibitive. The PCPA and MOGA will continue to advocate for the subsidisation of these high-cost drugs for patients with both common and rare tumours."

Professor Karen Canfell, Director of The Daffodil Centre and Stream lead for Cervical Cancer and HPV, underscored the importance of innovative approaches to clinical trial infrastructure.

"The current HTA review is an important process but it needs to be

responsive to new challenges. There is a need for new and innovative approaches to clinical trial infrastructure that can deal with some of the challenges about smaller subgroups of patients. Also, the investment in cancer research in Australia, unfortunately, isn't tracking with other countries in the OECD. The premature mortality and burden of disease is going to remain with us over the next quarter century."

Penny George, Director of Corporate Affairs at AstraZeneca, called for an "earlier, faster, fairer approach to cancer care" and recommended three key policies to enhance access. These include the establishment of an interim cancer drugs fund, subsidising genetic profiling for all cancer patients upon diagnosis, and separating funding decisions between cancer treatments and diagnostic testing.

Representatives from Roche, both in pharmaceuticals and diagnostics arms, were also present at the hearing. Ben Robinson, Head, Access and Innovation, Roche Diagnostics commented "We've seen delays of over eight years to reimburse access to pathology tests. Whilst there are comprehensive genomic tests currently being reimbursed in cancer, due to the way it's listed, it's not realistically available to all patients. This is having a direct impact on rare cancer patients and leading to inequitable care."

He added "There is an opportunity to accelerate the HTA process for all new in vitro diagnostics or pathology tests to 12 months, without compromising patient safety. There's also an opportunity for reimbursement decisions to factor in a broader range of benefits, which, if included, could support faster decision making."

Richard Woodfield, Country Medical Officer at Roche Pharmaceuticals, addressed challenges in translating research into standard care for rare and uncommon cancers.

"The lack of research translation leads to difficulties in attracting even

more research to Australia," he explained.

Mr Woodfield referred to the nation's largest cancer genomics initiative, PrOSPeCT (Precision Oncology Screening Platform Enabling Clinical Trials), spearheaded by Omico and supported in part by Roche. This initiative aims to establish a proof of concept for conducting comprehensive genomic profiling on patients with various cancers, both common and rare. The overarching goal is to attract clinical trials to Australia.

"That's a real example of how the pharmaceutical industry is engaging to be part of the solution. But again, the problem is that there's no long term certainty of being able to continue to invest in clinical genomic profiling in order to keep bringing those trials to Australia, once the funding runs out," he commented.

Christine Cockburn, CEO of Rare Cancers Australia (RCA), painted a vivid picture of the current situation, quoting Richard Vines, co-founder of RCA. She said "Someone once described the current situation as having patients drowning in the ocean whilst government and pharmaceutical companies argue about the price of the life jacket. Surely we can throw the life jacket to the patient and sort out the price after they are safe."

Ms Cockburn concluded by emphasising the urgency of action, stating, "It's time for us to act and make a difference for people with rare cancer. Without action and equity we cannot hope to improve the outcomes of people living with rare and less common cancers, and for them to have the same chance at life as everyone else."

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