

**Lung Neuroendocrine Tumor (NET) US Patient-Reported Experience: Results from the First Global NET Patient Survey—A Collaboration Between the International Neuroendocrine Cancer Alliance (INCA) and Novartis**

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**Background:** Lung NETs are rare, diverse tumors that are often asymptomatic, resulting in treatment delays and reduced survival. The burden of lung NETs on patients' lives has not previously been described.

**Methods:** In 2014, 1928 NET patients from >12 countries including the United States (n=758) participated in a survey, conducted by Hall & Partners on behalf of INCA/Novartis, funded by Novartis, on the NET patient experience (comparisons significant at  $P<0.05$ ).

**Results:** 15% of US patients had lung NETs, primarily nonfunctional/asymptomatic (53% of patients who knew status, n=79) and low grade (G1; 57%, n=70). 56% required  $\geq 2$  years for diagnosis; 49% were diagnosed with other conditions prior to NETs, most often asthma (56%) and pneumonia (35%). Most had not visited (64%)/been diagnosed (96%) at a NET specialist center. Lung NET patients were more likely to be

given the impression their cancer was curable (32%) and not something to worry about (40%) vs GI/pNETs (9%/14% and 23%/14%). However, similar to GI/pNETs (73%/74%), most lung NET patients (67%) experienced a moderate/large negative impact on quality of life and were more likely to temporarily stop working because of NETs (31%) vs GI/pNETs (12%/12%). Overall, patients with lung NETs had more negative feelings regarding health care provider expertise/knowledge and quality of care and were more likely to desire better access to NET experts (56%)/knowledgeable health care team (52%). Following diagnosis, fewer lung NET patients were satisfied they received answers to questions (43%) or sufficient information (33%) vs GI/pNETs (62%/59% and 48%/52%). 45% regarded quality of available treatments as poor/very poor (vs GI/pNETs [28%/33%]). Many (71%) expressed the need for more immediate access to NET specialists and transfers to NET centers of expertise (45%).

**Conclusion:** This large patient survey demonstrated the substantial burden of a lung NET diagnosis in the United States and identified areas for improvement.