Helsinn and PatientsLikeMe Announce Results of NSCLC Patient Survey on Weight Loss

San Francisco, September 09, 2016 – Helsinn Therapeutics (U.S.) Inc., the pharmaceutical group focused on building quality cancer care, and patient network PatientsLikeMe have unveiled findings from an online survey that captured experiences and insights about unintended weight loss and its burden among 95 patients living with non-small cell lung cancer (NSCLC). The study illustrates the importance of managing weight loss in cancer patients and is being presented in a poster at the Palliative Care in Oncology Symposium in San Francisco.

Unintended weight loss is known to negatively impact patients’ lives by reducing physical functioning, tolerance to anticancer therapy, quality of life and survival. Despite the poor prognosis and high prevalence, therapeutic interventions for unintended weight loss in cancer remain limited. The main objectives of the study were to characterize and compare the burden of NSCLC patients who reported considerable weight loss (≥ 5% of their body weight in the past 6 months or ≥ 2% for a BMI less than 20 kg/m²) with those who did not. Additionally, patient perspectives on how they view the importance and impact of weight loss were collected by asking open-ended questions modeled after the FDA’s Patient-Focused Drug Development Initiative. Study participants with self-reported, advanced NSCLC were recruited and surveyed on PatientsLikeMe.

As compared to participants without weight loss, study participants with weight loss reported significantly lower overall quality of life, worsened anorexia-cachexia symptoms and concerns, and higher symptomology, specifically fatigue, nausea and appetite loss. For patients with weight loss, change in food taste, fatigue and decrease in appetite were the most frequently reported symptoms with the greatest impact on their lives. Primary worries for these patients included loss of energy and disease progression.
Patients who lost considerable amounts of weight also voiced concerns about what worried them the most about weight loss ("I’m going to die faster, because my cancer will consume an unhealthy body, quickly"); the specific activities that are important to them but could not do anymore, or as fully because of their weight loss ("Don’t have the energy to clean the house and it is a struggle to make meals"); “Not being able to eat like I used to. I enjoy food so much.”); and other themes, such as the downsides to current treatments for their weight loss, and how it affects their daily lives ("Make it hard to cook for family"; “Feeling pain and constipation”; “Not being able to drive bothers me the most. It makes me feel helpless”; “For me, depression is a big downside”).

The study’s lead author is Eileen Mack Thorley, PatientsLikeMe Research Scientist. Authors from Helsinn include Dimple Aggarwal, John Friend and Elizabeth Duus. The poster is Abstract #17332: Experience of Weight Loss and its Burden in NSCLC Patients: Results of an Online Survey.

About the Helsinn Group

Helsinn is a privately owned cancer supportive care pharmaceutical group with an extensive portfolio of marketed products and a broad development pipeline. Since 1976, Helsinn has been improving the everyday lives of patients, guided by core family values of respect, integrity and quality, through a unique integrated licensing business model working with long standing partners in pharmaceuticals, medical devices and nutritional supplement products. Helsinn is headquartered in Lugano, Switzerland, with operating subsidiaries in Ireland and the US, a representative office in China, as well as a product presence in about 90 countries globally.

In 2016, our 40th anniversary year, you can meet representatives from Helsinn at:

- ChemOutsourcing Conference (Parsippany, New Jersey, 19-21 September)
- CPhI Worldwide (Barcelona, Spain, 4-6 October)
- ESMO Congress (Copenhagen, Denmark, 7-11 October)
- BioEurope (Köln, Germany, 4-6 November)
For more information, please visit www.helsinn.com

About PatientsLikeMe
PatientsLikeMe is a patient network that improves lives and a real-time research platform that advances medicine. Through the network, patients connect with others who have the same disease or condition and track and share their own experiences. In the process, they generate data about the real-world nature of disease that help researchers, pharmaceutical companies, regulators, providers, and nonprofits develop more effective products, services, and care. With more than 400,000 members, PatientsLikeMe is a trusted source for real-world disease information and a clinically robust resource that has published more than 70 research studies. Visit us at www.patientslikeme.com or follow us via our blog, Twitter or Facebook.

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