

News release

CTCL Global Care Collaborative Pioneers Consensus for Improving Diagnosis and Care in Cutaneous T-Cell Lymphoma (CTCL)

- *Patient advocacy groups form global collaborative to address unmet needs in CTCL, with support from Kyowa Kirin*
- *Consensus statement highlights 12 recommendations for healthcare authorities, hospitals, and clinicians to drive positive change for the global CTCL patient community*

Singapore, 14 May 2024 – Kyowa Kirin, Inc. a wholly owned subsidiary of Kyowa Kirin Co. Ltd, today announced the publication of a patient-focused global consensus statement – ‘[Time to Act: A Global Patient-Focused Consensus for Improving the Care of Cutaneous T-Cell Lymphoma \(CTCL\)](#)’ – developed in collaboration with patient advocacy groups.

The statement calls on healthcare authorities, hospitals, and clinicians to undertake 12 specific actions to enhance awareness, diagnosis, care, and support for people impacted by CTCL, which encompasses several types of rare blood cancer that primarily manifest in the skin.^{1,2}

The consensus statement is the inaugural output of the CTCL Global Care Collaborative, a newly established group united by a shared mission to reduce the time to an accurate diagnosis and improve the quality of care and support for people living with CTCL. Kyowa Kirin organizes and funds the group.

The Collaborative is focused on driving long-term change in four priority areas – improving awareness of CTCL amongst healthcare professionals (HCPs); improving time to diagnosis and awareness of disease staging; ensuring all patients have access to appropriate care; and empowering patients with the information they need to make informed decisions. The insights informing the group's work reflect global perspectives, the unique needs of the patient community, and international nuances.

“I'm delighted to join a global consensus on improving Cutaneous T-Cell Lymphoma (CTCL) care,” said Hong Fei, founder of HOUSE086. “CTCL, a rare lymphoma subtype worldwide, was added to China's rare disease list in August 2023, a positive signal. We look forward to collaborating on addressing unmet CTCL needs through education, training, and advocacy, aiming for positive changes for patients.”

“Due to the nature of CTCL, a skin-manifesting condition, a significant number of patients often miss the appropriate treatment window,” said Park Jung-suk, Director, Korea Blood Disease and Cancer Association. “Through this statement, KBDCA aims to promote accurate awareness of CTCL, preventing patients from being left to suffer unnoticed. We commit to continuing our efforts for social awareness change to benefit CTCL patients.” – Park Jung-Suk, Director, Korea Blood Disease and Cancer Association

CTCL can have debilitating physical, emotional, and social challenges. These are difficult enough to contend with, but their burden may be compounded by issues in testing, diagnosis, and care. Notably, in its most prominent subtype of mycosis fungoides (MF), the average time to diagnosis is 3-4 years.^{3,4} Like many rare diseases, issues in diagnosis may come from limited awareness and symptoms being mistaken for more common conditions. Once diagnosed, further health system issues, such as inaccurate disease staging and inequitable access to care, represent additional barriers for some patients. The Collaborative is dedicated to addressing these unmet needs globally.

“Patients’ unique knowledge and experiences living with CTCL hold the key to more fully recognizing the impact of this rare blood cancer and, hopefully, accelerating the improvement of awareness,

diagnosis and care in healthcare systems,” said Dr. Tan Boon Heon, President, Kyowa Kirin Asia Pacific. “Partnering the Collaborative’s patient organizations underscores Kyowa Kirin’s commitment to working with and delivering life-changing value to the CTCL community.”

To learn more about CTCL, the Global Care Collaborative, and the 12 recommendations, visit <https://www.kyowakirin.com/stories/index.html>.

About the CTCL Global Care Collaborative

The CTCL Global Care Collaborative aims to address the unmet needs faced by people living with CTCL, which encompasses several types of rare blood cancer that primarily manifest in the skin.^{1,2}

The Collaborative is organized and funded by Kyowa Kirin, a co-founder of the group.

It comprises global patient organizations – the **Cutaneous Lymphoma Foundation** and **Lymphoma Coalition**; national patient organizations – the **Spanish Association of People Affected by Lymphoma, Myeloma and Leukemia – AEAL** (Spain), the **Portuguese Association against Leukemia and Lymphoma – APCL** (Portugal), **Haukrebs-Netzwerk Deutschland e.V.** (Germany), **House086** (China), **Korea Blood Disease and Cancer Association** (South Korea), **Lymphoma Action** (UK), **Selbsthilfe Kutane Lymphome** (Germany) and **Stichting Huid Lymfoom** (the Netherlands); and Kyowa Kirin, a Japan based Global Specialty Pharmaceutical Company.

The physical and psychosocial burdens of CTCL can have a profound impact on those living with the disease. However, these burdens may be compounded by problems with testing, diagnosis, and care. This is why the Collaborative’s mission is to drive reform of healthcare systems globally and resolve the unmet needs that have persisted for those living with CTCL.

About Cutaneous T-Cell Lymphoma (CTCL)

CTCL can have debilitating physical, emotional, and social impacts. These are difficult enough to contend with, but their burden may be compounded by issues in testing, diagnosis, and management.

CTCL encompasses T-cell lymphomas affecting the skin.² CTCL is a rare subset of non-Hodgkin lymphomas.⁵

The best studied subtype of CTCL is MF, which accounts for 60% of CTCL cases.¹ Beyond MF, there are various other subtypes of CTCL, including Sézary syndrome, lymphomatoid papulosis, primary cutaneous anaplastic large cell lymphoma, and pagetoid reticulosis.⁶

CTCL can manifest as persistent skin patches and / or raised, scaly plaques, often with constant itching.⁷ More pronounced lesions can also occur.⁸ In MF, these symptoms and signs can frequently be mistaken for more common, benign conditions like psoriasis or eczema.³ As a result in MF, it can take 3-4 years on average for patients to receive a confirmed diagnosis.^{3,4}

CTCL is characterized by cancerous white blood cells (T-cells) primarily manifesting in the skin.² For some patients, the disease may evolve to also affect the blood, lymph nodes, and internal organs.⁹ CTCL is treatable, but not generally considered to be curable.²

About Kyowa Kirin

Kyowa Kirin aims to discover and deliver novel medicines and treatments with life-changing value. As a Japan-based Global Specialty Pharmaceutical Company, we have invested in drug discovery and biotechnology innovation for more than 70 years and are currently working to engineer the next generation of antibodies and cell and gene therapies with the potential to help patients with high unmet medical needs, such as bone & mineral, intractable hematological diseases/hemato oncology, and rare diseases. A shared commitment to our values, to sustainable growth, and to making people smile unites us across the globe.

You can learn more about the business of Kyowa Kirin at: <https://www.kyowakirin.com>.

Contact:

Corinne Lim

corinne.lim.c9@kyowakirin.com

References

- ¹ Willemze R, et al. The 2018 update of the WHO-EORTC classification for primary cutaneous lymphomas. *Blood*. 2019;133(16):1703-1714.
- ² Cleveland Clinic. Cutaneous T-Cell Lymphoma. Available from <https://my.clevelandclinic.org/health/diseases/17940-cutaneous-t-cell-lymphoma>. Last Accessed: May 2024.
- ³ Wilcox RA. Cutaneous T-cell lymphoma: 2016 update on diagnosis, risk-stratification, and management. *Am J Hematol*. 2016;91(1):151-65.
- ⁴ Scarisbrick J, et al. The PROCLIP international registry of early-stage mycosis fungoides identifies substantial diagnostic delay in most patients. *Br J Dermatol*. 2019;181(20):350-357.
- ⁵ Trautinger F, et al. European Organisation for Research and Treatment of Cancer consensus recommendations for the treatment of mycosis fungoides/Sézary syndrome - Update 2017. *Euro J Cancer*. 2017;77:57-74.
- ⁶ Girardi M, et al. The Pathogenesis of Mycosis Fungoides. *New Eng J Med*. 2004;350(19):1978-88.
- ⁷ Demierre M-F, et al. Significant impact of cutaneous T-cell lymphoma on patients' quality of life. *Cancer*. 2006;107(10):2504-2511.
- ⁸ Bagherani, N, et al. An Overview of Cutaneous T-Cell Lymphomas. *F1000 Research*. 2016;5:F1000 Faculty Rev-1882.
- ⁹ Olsen E, et al. Revisions to the staging and classification of mycosis fungoides and Sezary syndrome: a proposal of the International Society for Cutaneous Lymphomas (ISCL) and the cutaneous lymphoma task force of the European Organization of Research and Treatment of Cancer (EORTC). *Blood*. 2007;110(6):1713-22.