

News release

For pharmaceutical/medical media

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*

Tokyo, Japan., 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.

Dallas Pounds, Director of Services for Lymphoma Action UK, a patient organization in the Collaborative, said: “I’ve witnessed the debilitating challenges of misdiagnoses, delayed treatment, and unequal access to care for those living with CTCL. The consensus statement is an important publication for the global CTCL community, addressing the issues in disease awareness, access to care, and patient communication. It’s a vital milestone for those living with CTCL, and I’m proud that patient organizations have united from across the world to drive change in healthcare systems for the benefit of those struggling with this debilitating disease.”

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.

Jeremy Morgan, President, Kyowa Kirin International, commented: “At Kyowa Kirin, one of our core values is Commitment to Life, ensuring the patient perspective is at the heart of everything we do. Testament to this value is our role as one of the founding partners of the CTCL Global Care Collaborative. We’re honoured to be working with the CTCL community to help address long-standing issues in diagnosis, care, and support. These are unmet needs that have persisted in CTCL, and together I am confident we can drive transformational change in healthcare systems globally.”

To learn more about CTCL, the Global Care Collaborative, and the 12 recommendations, [click here](#).

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 is comprised of global patient organizations – the **Cutaneous Lymphoma Foundation and Lymphoma Coalition**; national patient organizations – **Lymphoma Action** (UK), the **Portuguese Association against Leukemia and Lymphoma – APCL** (Portugal), the **Spanish Association of People Affected by Lymphoma, Myeloma and Leukemia – AEAL** (Spain), **Stichting Huid Lymfoom** (the Netherlands) and **Haukrebs-Netzwerk Deutschland e.V.** (Germany); **Selbsthilfe Kutane Lymphome** (Germany), **Korea Blood Disease and Cancer Association** (South Korea), and **House086** (China); 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 characterised 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://international.kyowa-kirin.com/>.

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