

# INTERNATIONAL LYMPHOMA PATIENT CHARTER

RATIFIED BY LYMPHOMA COALITION MEMBERS September 2017

This international charter was created to ensure that the more than one million people living with lymphoma worldwide<sup>1</sup> have access to the best available care, information and support. The number of lymphoma cases is increasing rapidly<sup>2</sup> and there is a critical need for patients to be better informed regarding their subtype.<sup>3</sup>

Much can be done to improve the current situation and this is the responsibility of society as a whole, including healthcare professionals, patient groups/advocates, governments, insurers, payors/funders, clinicians, researchers and industry. To ensure that patients living with lymphoma receive the best care available, it is vital that the rights outlined in this charter are adopted globally.

With the high degree of focus on "patient centricity", the Lymphoma Coalition patient body who are the recipients of the behaviour driven by this term, defines it as the following:

- Engaging individuals with lymphoma, and their caregivers in all aspects of their care, tailoring support with the understanding that every patient is unique with a different set of complex needs that may change over time.
- Giving the lymphoma patient, and those close to them, a voice so that the focus of their care and needs are included throughout the decision-making process.
- Listening to and hearing the person affected by lymphoma respecting their culture, input, dignity, intelligence and capacity to make informed decisions about the impact on their lives and their care.
- Including patient organisations as active partners representing a patient's emotional and psychosocial needs at every stage of care including; treatment, protocol development and by informing research throughout the clinical and treatment development continuum.

## DIAGNOSIS

All patients living with lymphoma are entitled to timely investigation and an accurate diagnosis by a qualified medical expert with a specialty in blood diseases such as haematopathology. It is critical that specialised imaging, scanning and molecular testing are utilised to determine the exact subtype and the extent of subtype progression for appropriate treatment planning. All patients are entitled to a second opinion and referral to a haematopathologist, who can review their case and diagnostic material.

## TREATMENT

Patients are entitled to have access to optimal treatment, based on an accurate diagnosis, stage and current evidence-based medicine. Patients have a right to know about all available treatment options and should be informed of relevant clinical trials. Financial status should neither be a barrier nor a determining factor in informing patients about treatment options, as all patients have a right to optimal treatment and it is in their best interest to know about the latest advances in the field. Patients are entitled to be an active participant in the treatment decision-making process.

## FOLLOW-UP

Because lymphoma can recur, patients are entitled to regular follow-up care and close monitoring. Patients living with lymphoma have a right to receive a continuum of care provided by a dedicated team of healthcare specialists. Long-term follow-up and ongoing interaction between all of these parties and the patient is crucial to determine the best course of action.

## INFORMATION

Patients are entitled to be provided with all necessary information regarding their diagnosis, treatment and overall subtype management and should be encouraged to become active participants in the treatment decision process. This information should include:

- 1) subtype
- 2) treatment options
- 3) risks and side effects of treatment
- 4) clinical trial opportunities
- 5) patient support tools and patient organisations

## SUPPORT

Patients are entitled to be informed of all available support systems. Patients are entitled to have a "voice" in their own subtype management. Patient support tools and patient organisations can play a key role in a patient's recovery process and can help them access a host of resources, from psychological support to family counselling. Through these groups, patients can also become involved in health policy discussions that can impact confidence and subtype management for all patients living with lymphoma. Having the right support network is invaluable for patients at all stages of their illness.

### References:

1. GLOBOCAN 2002: Descriptive Epidemiology Group of the International Agency for Research on Cancer (IARC)
2. <http://www.lymphoma.org/site/pp.asp?c=bFKIVMIG&b=38240>
3. NOP September 2005 data on file