The "I" ask – if not now (or very soon)… when?

Stephen Kelland

Impact, Impetus and *Interest*: the "I"s have it … do the "ayes"?

While the figurative Lymphoedema ship of good fortune is woefully delayed, it has not yet sailed! So, if not now (or very soon!)… when?

This piece by LymphoGWG is not a call *to* arms, but rather a call *for* arms… plus legs, torsos, hands, feet, neck, head and anywhere else where that 'scourge' of a chronic, progressive, incurable disease, Lymphedema/Lymphoedema (LE), wreaks havoc on the body human. Loyal to the communications golden rule of 3s, this pitch is a straightforward appeal to help improve the quality and quantity of life for the world's population of LE afflictees.

Borrowing from a cinematic history technique, specifically 1966's Italian spaghetti western *The Good, The Bad, and The Ugly*, the three ordered variables make their introductory appearance in reverse order for this plea with rationale, i.e., *Interest*, *Impetus* and *Impact*.

Interest

Your scribe deals in practical matters of seeking tangible, but lasting, help for the world's estimated 300 million LE "afflictees", some of whom are fortunate enough to be medically attended "patients". (The notion of a type of promotion or graduation from *afflictee* to *patient* will be addressed, further below.) As such, pragmatism is (or has been) preferred over philosophy in LymphoGWG's appeals, overtures, and engagement efforts for "the cause". Suffice it to state, the mounting series of results are sadly and underwhelmingly about the same. Simple, straightforward and strategic solutions humbly (but repeatedly) proposed to the LE world leaders are eschewed, seemingly, for preferred attention to continued harvesting of low-hanging-fruit-type "achievements". Small wonder that tangible, lasting, beneficial change for LE afflictees moves at a glacial pace. LymphoGWG is painfully and personally aware of this reality: he is not only a long-time advocate-at-large for "the cause", but also a longer-time afflictee presenting with a complex case of primary LE. Additionally, he is equally cognisant that "awareness" of a problem, *per se*, is not always a likely precursor for a solution or remedy to the problem to be forthcoming.

As you are part of the readership of this global publication for LE, permit the author to presume that interest (*your* interest) in the plight of afflictees is a given. Thank you for that interest!

Stephen Kelland is 'Lymphedema – Guerrilla Warrior General' (LymphoGWG), advocate-at-large for "the cause" of the fight versus lymphedema (LE), and is based in Ottawa, Canada

Impetus

The persona behind the advocate (LymphoGWG) is, himself, a long-time LE afflictee. Employing and deploying the maxim to "think like someone of action and act like someone of thought", LymphoGWG has conducted many active, successful, and strategic campaigns to promote attention (education, recognition, and understanding) among many targeted publics, often emphasising the LymphoGWG-styled "PSA".[1]

Extremely appreciative of the reach and prominent platform again graciously provided by this global publication (earlier perspectives in the *Journal of Lymphoedema* appear in the recent issues 2022–2025), the LymphoGWG 2026 offering is more subdued… cerebral-driven, if you will. To instigate or initiate an impetus, this advocate applies his variation of the timeless approach from ancient Greece, the Socratic method. LymphoGWG's expressed goal is to stimulate curiosity as 'food for thought' of the *JoL* readership, leading (hopefully) to supportive action. Delving into his own, lengthy, plus continuing LE journey, LymphoGWG has found that curiosity, complemented by vigorous intellect (constant learning) and dogged perseverance, is the three-part key to a modicum of life… living with LE.

The Socratic method, briefly, is a dialogue between teacher and students, with continual probing to arrive at answers after a full exploration of underlying beliefs, views, and opinions. Rather than making heartfelt pleas based on his own "lived" experience with LE, and the medical/health-care construct that should treat it, LymphoGWG hopes this inquiry-type piece will achieve a better outcome (and impact!). The individual after whom the method is named was Socrates, a prominent figure in ancient Greek philosophy. Ironically, sources consulted by LymphoGWG indicate that the Socratic method is often used in medical education.

So, the "impetus" takes the form of a quest for thoughtful, meaningful, and hopeful answers that naturally spring to mind for LE afflictees.

Now, then, the first salient question for this Socratic method exercise serves to underscore the mission to achieve beneficial and lasting change for "the cause" (our cause): "*If not now (or very soon!)… when?*"

Any afflictee of LE might well pose several of the following anxious queries:

- What is wrong with me? Or, what do I have?
- Why is my (foot/leg, hand/arm, torso, head/neck, genitalia, other or combination) so swollen?
- What can I do?
- Who can I see for answers/help?
- Where do I go?
- How do I find answers?
- Why does my doctor/physician not know what is wrong with me?

Any/all of the foregoing Socrates-type curiosities would be (are) quite understandable.

The ensuing "impact" element could be envisioned with the examination of some possible answers to these concerns/worries/fears, all borne of urgent curiosity. Further, to understand why such answers might be difficult to receive in current

healthcare constructs, perhaps a compare-and-contrast-type perspective would aid the thought process… in seeking true, literal philosophy, i.e. "love of wisdom" from ancient Greek.

Permit me a slight detour to make a comparator point.

Goes a philosophical question: *"If a tree falls in the forest and no one is there to hear it, does it make a sound?"* Employing a metaphorical twist, LymphoGWG ponders whether a tree falling in the forest could be equated to the voice of a patient-advocate making a (repeated) appeal? Pointedly and quite seriously: if nothing happens – was the voice heard? Was the plea listened to, at all? Was the appeal understood? – without any acknowledgement from the LE world powers that be (leadership?), much less feedback and/or evidence of reaction/action! – then was the cry really uttered, written, or otherwise communicated? Tough realities lurk behind such questions for LE folks who are seeking some LE *philosophy*!



Stephen Kelland as "LymphoGWG" with spouse, Elaine McArdle, #1 Supporter and Co-Champion for the Cause – Ottawa, Canada.

Impact

To illustrate a sense of what impact is sought, picture a snapshot of the LymphoGWG approach. Based out of Canada's capital from "Lymph Nexus Canada" (Facebook/Meta), LymphoGWG's pursuits are anywhere and everywhere in realities (virtual plus real), Canada-wide and well beyond (notably including, America, Italy, and Austria). Widespread campaigns have taken the forms of:

- *Words* (SOS4WLD – "Statements of Support for World Lymphedema Day");
- *Gestures* (Lit4LE – special lymph-green tribute illuminations of significant landmarks in recognition of the fight versus Lymphedema); plus,
- Many other supportive measures.

This afflictee/patient-advocate operates year-round, especially since 2001 (25 years ago was when long-haul air travel significantly exacerbated his complex presentation of primary LE, prompting the mission purposes of LymphoGWG, formerly as Canada MALE – **M**ale **A**dvocate (for) **L**ymph**E**dema).

LymphoGWG's very personal, driving rationale is borne of the sad reality that LE can be (is) a medically marginalising and socially stigmatising disease, with limited help for the afflictees.

The overarching goal envisioned is the following impact: that any/all afflictee (whether a female "*Lymphie*" or male "*Lympho*" type) will beneficially achieve the "*X factor*" quadfecta status of "patient" mentioned in previous comments in this journal. A reminder that the "*X factor*" quadfecta is:

- *Dx* – timely, competent diagnosis;
- *Rx* – prescribed, LE-savvy care;
- *Tx* – case-specific and appropriate treatment on the continuum of proven modalities ranging from (intensive) conservative to (micro) surgical intervention; and,
- *Px* – the prognosis of a modicum of all-important **hope,** leading to an enhanced quality, plus quantity, of life/living.

As mentioned in previous comments in this series, "*afflictee*" is a nameless, helpless, and often hopeless statistic for whom no attention nor care is administered, even though the individual is afflicted with a serious, chronic, progressive disease for which there is (yet!) no cure. By contrast, an afflictee who has achieved the foregoing beneficial "*X factor*" status as an attended, named "*patient*", is assisted with competent, compassionate, LE-savvy care and treatment, with hope restored.

Approach… "Aye" to "I" (times 3)

Taking the form of three complementary terms, *Care*, *Community* and *Communications*, the "prescription" that we would/could/should achieve takes shape in the format of three resolutions articulating the ideas, which have been submitted to leadership of the world's foremost body of practitioners, including the International Society of Lymphology (ISL), plus some of the globe's leading organisations for LE- and LD-related interests – the International Lymphoedema Framework, the Lymphatic Education and Research Network and the National Lymphedema Network – calling for the establishment of "*Lymph Day – 23 July*", annually. Abridged versions of the three resolutions appear below, and the embodiment of one (*Community*) appears in the graphic that accompanies this piece.

1. ***Care*** – formal motion-resolution for ISL-World Congress of Lymphology (WCL) executive leadership @ WCL2023 – Genoa, Italy [from LymphoGWG Canada @ 11 June 2023; re-submitted @ 15 March 2025]. ***Resolution*** – Why is there no recognised, certified, and credentialed medical specialty of lymphology… anywhere or, better yet, everywhere?
2. ***Community*** – formal motion-resolution for ISL-WCL executive leadership @ WCL2025 – Antalya, Türkiye [from LymphoGWG Canada @ 21 July 2025]. ***Resolution*** – Establishment of "Lymph Day", on 23 July 2026 … annually and everywhere!
3. ***Communications*** – formal motion-resolution for ISL-WCL executive leadership, care of ISL President @ WCL2025 – Antalya, Türkiye [from LymphoGWG Canada @ 28 November 2025]. ***Resolution*** (excerpted from "*Getting Real!*" presentation to ISL's

Lymph Day
(established 23 July 2026)

Whereas, Lymph/Lymphatics are critical to the functioning of the body human for eight (8) billion beings, and form the basis of Lymphology, the medical and scientific study involving beneficial components of anatomy and physiology in addition to the detriments of pathology (diseases and disorders); and,

Whereas, Lymphedema (LE) is a chronic, progressive, incurable lymphatic disease (LD) characterized as an accumulation of high-protein lymphatic fluid that causes swelling (edema) in several bodily regions and can have severe physical, emotional, psychosocial, and financial impacts and effects on the estimated 300 million global afflictees plus their families; and,

Whereas, "Lymphedema Awareness Day" (LAD) was established by the National Lymphedema Network (NLN) in 1994, to honour patients, caregivers, and healthcare providers, while raising regionalized awareness of LE; and,

Whereas, "World Lymphedema Day" (WLD) was established by the Lymphatic Education and Research Network (LE&RN) in 2016, to improve upon LAD, prompting global attention plus action, with more than mere awareness, to educate the public and medical community(ies) about LE, by promoting research, advocating for better treatments, and reducing stigma; and,

Whereas, Lymphology is a discipline that studies structure, function, and clinical management, notably under the aegis of the International Society of Lymphology (ISL), ISL leadership has a significant opportunity at circa 2026 to further progress the cause; and,

Whereas, 23 July holds tremendous significance for Lymph
(1966: establishment of the ISL, and 400-plus years ago: Gaspare Aselli makes lymphatics discovery in the "Cradle of Lymphology");

Therefore, ISL Executive declares 23 July 2026 and henceforth, the establishment of "Lymph Day", to ensure Lymph/Lymphology/LDs (notably LE) ascend to a rightful place among public health agenda issues on the world stage, with the goal of universal availability, accessibility, and affordability of care.

Lymph Day - 23 July: THE day we need… "If not now, when?"

WCL2025) – seeking: *a more concerted, consistent, comprehensive, and courtesy-driven approach to communications, including informative out-reporting from such important fora as the biennial congress, inclusion of afflictee or patient perspectives in the Lymphology Journal, plus complimentary opportunity for stakeholder membership capacity (ex. Associate, Affiliate or Friend of the ISL).*

Against the backdrop of the aforementioned questions (impetus), the imagined impact would be the following.

Care:

- Hope of the afflictee, replacing fear, concern, and hopelessness.
- Status improvement from "afflictee" left to fend for oneself to "patient" who is medically attended by competent, caring, and compassionate practitioners.
- When/where a general practitioner feels un- or ill-equipped to fully, properly, medically attend a patient, the referral to a more qualified resource (Hippocratic Oath provision) would be more evident and possible… we would have recognised, certified, and credentialed medical specialists (lymphologists, i.e. formally qualified in the physiology, pathology, and structure of the lymphatics… not merely by self-assessment/appointment with "interest" in lymphatics or some understanding, but outside of one's primary, specialised scope of practice).

Community:

- A forged, coalesced, strengthened, and unified "*Lymph Community*" (lymphology/lymphatics) rather than a series of siloed "collectivities" representing subsets of lymph/lymphology.
- A "community" bolstered and thoroughly reinforced by *veritas* of the afflictee-patient voice along with the *gravitas* of the practitioner expertise to form a proper *unitas* force for any/all concerted efforts to advance "our cause."

Communications:

- Piggybacking on the hopefulness, recognition, and understanding engendered by the above, there would be a greater environment of exchanges and belonging, ex. much like most organisations serving various "collectivities" have tiered membership, the esteemed ISL would extend an opportunity for afflictees-patients-advocates to "belong" in some manner.

Thank you for your time and attention, dear reader. Circling back to the outset of this perspective piece, *"If not now (or very soon!)… when?"*, LymphoGWG suggests that a considerable and beneficial "impact" could well be upon us, *if* decision-makers were to exercise leadership.

"To you from failing hands we throw the torch; be yours to hold it high."

These words are the immortal closing lines of "In Flanders Fields", a World War I poem written by Canadian doctor and Lieutenant-Colonel John McCrae in 1915. The verses serve as a plea from fallen soldiers, urging the living to carry on their legacy and the cause for which they died. Emphasising that although LymphoGWG is a figurative warrior, who has not taken up arms as a soldier, his poetic licence expands "failing hands" to "failing limbs (LE)", while making the point that his "*Lympho*" energy is low, his patience is near depletion, and fatigue is growing with "leaders" who fail to act.

Good lymphatic health!

Lymphedema - Guerrilla Warrior General (LymphoGWG) welcomes comments at LymphoGWG@gmail.com.

1. For a refined 'public service announcement' approach with targeted publics, the LymphoGWG-styled "PSA" is, as follows:
"P" (#PrognosisNotPity) – to mainstream medical/research community leadership for appropriate, case-specific, LE-savvy diagnosis, treatment & care;
"S" (#SolutionsNotSympathy) – to socio-political leadership for resources; and,
"A" (#AgencyNotApathy) – to otherwise apathetic afflictees, their caregivers, loved ones and other supporters… plus leadership of Lymphedema/Lymphoedema, Lymphology, & lymphatic organisations.