Getting real! It's time … and about more than just time

Stephen Kelland

Whether you term it as overtime or extra time, or even 'last call' at your favourite watering-hole establishment, it is time… and about more than just time. It's time for getting real!

It's about… Care, Community, and Communications, where the 21st century cause for *Lymph* is concerned.

Dear *Journal of Lymphoedema* (*JoL*) reader, hoping you have read instalments one, two, three as fortunately graced the platform pages of this global Lymphoedema/Lymphedema publication in 2022-2023-2024, this final piece gels a "*Lympho*" perspective on the green-light pathway to Lymph success: what is needed and from whom.

Your scribe is Stephen Kelland, in his capacity as "Lymphedema – Guerrilla Warrior General" or simply "LymphoGWG". I am a long-time Advocate-at-Large for "the cause" of the fight versus Lymphedema. For context and disclosure purposes, as LymphoGWG, I am a very long-time afflictee, of more than four decades, who has a complex presentation of primary/hereditary Lymphedema (LE).

With renewed thanks to the editorial team at *JoL*, this "time" piece presents an afflictee's prescription on what could, would and should happen to help the cause of Lymph. I am talking about Lymphology – the pathology plus the physiology – taking its rightful place on the radar of the world's public health- or medical-care agenda.

Employing substantial "*lived and learned*" experiences, including as a forced "*medical tourist*" to more LE-savvy countries than my own (Canada), I offer a straightforward remedy for the cause… OUR cause.

The LymphoGWG perspective, or truly "*prescription*", for Lymph's green-light pathway to success is relayed with the injection of personal realities from my continuing LE journey. The underlying reality is that I am a triple-niche afflictee, given that my presentation of this chronic disease is:

- Primary, rather than the more prevalent secondary or acquired LE;
- Comprehensive, affecting my body from umbilicus to toes, rather than a more straightforward case of extremity-only impact; plus,
- Plaguing a male body rather than one of the "lioness' share" of female bodies.

With disclosure and first-hand credentials out of the way, on to the prescription where the number three (3) figures prominently. The three Cs are:

- Care;
- Community; and,
- Communications.

Further, the letter "X" also very much plays a supporting role in the equation. There will be more on the "X", later, including terms of how LE afflictees are treated in the medical- and health-care systems.

To begin…

Care

This segment takes influence from the 19th century English polymath, Herbert Spencer, who stated: "*The great aim of education is *not* knowledge, but action.*"

That quote well sums up the main intent of LymphoGWG's advocacy.

It complements the notion of what I term as the elusive "X factor" that all of the world's estimated 300 million afflictees would be truly blessed to achieve, that is as cared-for and medically attended "patients" rather than mere statistical "afflictees", who are otherwise isolated and left to their own devices, or, alone, trying to cope with a socially stigmatising plus medically marginalising "condition". A "condition", I hasten to add, that is really a progressive, chronic, and incurable scourge of a disease.

The term "X factor" is generally regarded as an undefinable, intangible variable that can often mean the difference between success and failure, such as for a cause. This notion of an "X factor" as it applies to an afflictee of LE can be related to a location, like one might seek out an "X" on a map. Equally, it can mean success in applying some medical shorthand (or medicalese) to one's situation… like the LymphoGWG-coined "X factor" quadfecta, which is:

- *Dx* – timely and competent diagnosis;
- *Rx* – prescriptive, LE-savvy care;
- *Tx* – case-specific, appropriate treatment on the continuum of proven modalities of care ranging from (intensive) conservative to (micro) surgical intervention; leading to,
- *Px* – an improved prognosis for quality plus quantity of life/living for the 'afflictee' in her/his attended 'patient' status.

Regardless of evident symptomology becoming apparent, a medical practitioner must have the education and training to take action, which is to identify and understand the presence of a chronic disease (which is progressive). Too many afflictees go unattended, leading to feelings of frustration, hopelessness, and despair.

As for the other "X factor" alluded to earlier, akin to finding an "X" location, one should not need an international map for seeking (and achieving) help as an afflictee of LE or other lymphatic diseases (LDs).

Unfortunately, as this advocate-at-large has long ago lived and learned… *should*, *could* and *would* are not readily interchangeable where one's health is concerned.

One would truly be a fool to hold this expectation… at least where LDs are concerned.

Sadly, if not for personal drive and determination, among other characteristics (aided by a God-given dose of good luck!), this LE afflictee would not have achieved the

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

beneficial "X factor" quadfecta as a 'patient'. Mind you, this achievement was only possible after several years of painstaking effort and energy, plus considerable expended resources to travel to more LE-savvy countries like Austria and Italy.

The problem, like many things in life, is crystal clear… in hindsight!

After all, "*doctors treat what they know*." As presented in research from Canada, the US, Australia and other countries, doctors-in-training at post-secondary medical schools receive very limited study time in the lymphatics.

Formal requests I have repeatedly made to the leadership of Canada's 17 medical schools did little, if anything, to dispel these findings.

Straightforwardly, my correspondence to deans, presidents, principals, and the like who lead these institutions, posed two basic questions:

1. is lymphatics being taught in Canadian medical institutions?

And, if yes…

2. in what degree (for example, how much time during medical school curricula studies)?

As my home-base city has a medical school, the University of Ottawa, I further amplified my specific requests for the Dean of Medical Studies, there, by:

1. seeking answers to the two earlier questions posed to all Canadian medical schools; plus,
2. seeking the opportunity to meet and receive a copy of the curriculum syllabus as relates to lymphatics and Lymphology; and,
3. seeking the opportunity, sometime during the academic study or practice term, to attend when/where the aforementioned curriculum matters would be presented and instructed at the University of Ottawa medical campus.

Needless to state, the request was summarily denied, citing "proprietary protection" for the institution's curriculum.

The result means that with **no** credentialed, certified and recognised medical specialty of Lymphology in Canada, plus **no** way of comprehending why family physicians or general practitioners often have *no* clue about lymphatic issues, the possibility for a Canadian LE afflictee to achieve the beneficial "X factor" status of "patient" is… extremely difficult.

Pictured is the author, Lymphedema – Guerrilla Warrior General (LymphoGWG), Advocate-at-Large for *the cause* of the fight against lymphedema.

For clarity, before moving on from Care to Community, I emphasise a distinct and vastly important differentiation I make between being a hopeless, unattended statistic as an "afflictee" compared to a medically attended plus cared-for individual who has fortunately attained the beneficial status of "patient".

Community

For the second segment, Community, I borrow an apt turn of phrase from Sir Winston Churchill, who once said: "*However beautiful the strategy, you should occasionally look at the results.*"

Bluntly stated, dear *JoL* reader, whatever "strategy" is at play for LD afflictees, is **not** working. From the myriad of well-intentioned organisations that give voice to such siloed 'collectivities' as represent LE, lipedema, other LDs, plus the esteemed practitioners of Lymphology, conspicuously absent is a lodestar that could, would, should serve to unite these groups for the advancement of the shared cause. There is *not*, (or at least not yet!), a singular group, like what is needed. I refer to a coalesced, forged, strengthened sense of *unitas*… for a worldwide "Lymph Community".

I speak of a group that could/would have shared goals, active engagement, a sense of true belonging plus strong communications.

Leaving the "communications" element aside, for the purposes of this segment, a strong triad needs to emerge to aid THE cause:

1. *Veritas* – the truth element that afflictees or patients bring to the equation;
2. *Gravitas* – the seriousness that practitioners of Lymphology shine on the situation; and,
3. *Unitas* – the state of oneness, which the combination of veritas and gravitas

would impart on the social conscience of the general public, where all things Lymph are concerned.

To solidify the point, the words of Roman ruler Julius Caesar suffice, with some adaptation. Caesar famously cried: "*Veni, vidi, vici*", which is Latin for "*I came, I saw, I conquered*". Adapting from this old maxim, LymphoGWG viscerally feels that we need: "*venimus, vidimus, vicimus*"… "*WE came, WE saw, WE conquered*".

The aforementioned "WE" is (or at least "*would/should/could*" be) the soon-to-be-established, and unified, "Lymph Community". One hopes, as this one (LymphoGWG) assuredly does, and one also acts toward that aspiration for materialisation on 23 July 2026 (more on why that particular date, later in the "prescription").

The unfortunate absence of an evident global "Lymph Community" has been raised by this advocate-at-large several times and on numerous media platforms, previously. So, today, I will briefly dwell only on what I have termed the "highest common denominator" approach to advocacy for Lymph.

The term segues eloquently with the education goal of action, just described, while also dovetailing with the "Communications" segment later in this piece.

From my many promotional campaigns for attention, education, understanding plus recognition for "*the cause*" – including with fundraising efforts – I have shifted targeted publics' awareness using metrics of a much larger scale. True, as often shared by various reputable sources, the estimated prevalence of LE is at 300 million, worldwide. However, the traction or engagement for this demographic has been limited and regional at best.

But, deep breath here, readers, ***if*** a concerted effort were made to engage the whole of humanity, say the health interests of approximately 8 billion beings… surely, society, writ large, would be more predisposed to at least listening to the message on the importance of Lymph, Lymphology and lymphatics.

A truly community-minded approach could accomplish that.

I further add that the "Lymph Community" would do well to standardise the terminology, spelling, plus associated symbols, and colours for "*the cause*", to increase its likelihood of success.

(For a prime example of what this would entail, I invite all *JoL* readers to consult their annual calendars for 4 February's "World Cancer Day" … and yes, the global English-speaking population does all spell CANCER the same way.)

Communications

If you were keeping count, this brings me to the final "C" segment of Communications.

To initiate this segment, I turn to the epiphany of a surreal character by the name of Pogo, who from the politically charged 1940s page of an American daily comic strip revealed: "*We have seen the enemy and he is us.*"

Taking into account the proposals advocated for Care and Community, I believe it is clear how, at least conceivably, that we are our own worst enemy where communications are involved for "the united cause".

Rather than expounding the several ways Pogo's observation is true, I cite but two examples using the LE "collectivity", namely spelling and associated colour.

Spelling – while items on the list of significant maladies that compete for public, policy-maker, and decision-taker attention are often recognized, understood, and supported at first mention, often even in abbreviation like AIDS, ALS, MD or MS, LE is ***not*** even described in consistent terms within the English-speaking world. Confusing and complicating our own message does ***not*** augur well for a cause that is seeking recognition plus associated support. Standardised spelling would certainly help not only the Communications component of the *Lymph* prescription, but also its related Care and Community needs!

Colour – in my active, engaged involvement of promotional campaigns for LE, I have seen everything from light blue, to dark blue, to teal, and even yellow, in competition with "Lymph-green". While wording can tremendously support efforts for a cause, colour recognition for belonging is often more immediate. Given that medical school textbooks plus promotional/marketing posters of durable-good manufacturers in the LE marketplace have long employed green to depict Lymph… why is this not consistently replicated in helpful campaigns… everywhere?

In my closing line of reasoning before presenting the full and finalised prescription, I paraphrase a biblical source, the Gospel according to St Luke, fittingly the patron saint of physicians and surgeons (Luke 12:48). Its meaning is apt for those whom this piece is eventually intended to persuade and prompt into positive, united action, i.e. leadership of 'collectivities' that include the International Society of Lymphology (ISL), in addition to the International Lymphoedema Framework (ILF), Lymphatic Education & Research Network (LE&RN), National Lymphedema Network (NLN) and other well-established entities with some sway in how Lymph, Lymphology and lymphatics are treated. The phrase is: "*To whom much is given, much is expected.*"

While, yes, the accomplished leadership cadre of the aforementioned organisations surely earned what has been given to them, the idea is that those who have been blessed with significant advantages, talents, or gifts, are expected to use them wisely, and for the betterment of society. Please bear this in mind, dear *JoL* readers, when communicating with various influential leaders the notion that the "Lymph Community" is very much a part of their society.

Conclusion

And there you have it, dear *JoL* readers, the three-part thesis on the green-light pathway to Lymph success. As for the identification on what is needed and from whom to achieve this success... LymphoGWG offers a succinct three-part prescription for consideration, please.

Care: ISL leadership – why is Lymphology ***not*** a recognised, certified and credentialed medical specialty, EVERYWHERE?

Please, I urge you to consider the context of "Care" outlined in this piece, including the Herbert Spencer quote regarding the goal of education. Then, maybe consider how you can help the cause, everywhere! Without recognised, certified, credentialed medical lymphologists… to whom can LE/LD afflictees turn?

Community: ISL/ILF et al leadership – Proposal: establishment of a "World Lymph

Day", each 23 July, beginning in 2026, to coincide with the 60th anniversary of the ISL (fitting time). Leaders, please consider the context of "strategy" evaluation as voiced by Churchill. We need a better strategy for THE "Lymph Community". July 23rd would be an excellent choice for this day, given its historical link to the Milan (ITA) discovery of Gaspare Aselli, more than 400 years ago, plus, more recently, the close of the 1966 Zurich (CH) forum to establish the ISL.

Communications: All Lymph-related 'collectivity' entities – Proposal: please, initiate (and maintain) a more consistent, comprehensive, and courtesy-driven approach to "communications". This would include informative out-reporting from such important fora as annual/biennial conferences and congresses, plus open-source sharing of other important developments. Inclusion of afflictee, patient and/or advocate perspectives in the associated communications arms of all collectivities' platforms would also be helpful (e.g. *Journal of Lymphoedema* and *Lymphology Journal*).

Rest assured, the *Lymph* world would be incredibly grateful if/when this prescription were filled!

Thank you – good lymphatic health.

- *Please note that the author uses "Lymphedema" to show the problem of standardisation of English-language spelling.*
- *Lymphedema - Guerrilla Warrior General (LymphoGWG) welcomes comments at Facebook 'Lymph Nexus Canada' where the mission tag line remains: "Shrinking the Lymphedema World, while Strengthening the Lymphedema Community… upside & down under!"*

LymphoGWG extends heartfelt appreciation to the global publication **Journal of Lymphoedema** *for affording this platform.*