

“Highest common denominator”: is it (yet) time to ‘green light’ a better ‘hook’ for “the cause” ... a perspective anew?

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“The great aim of education is not knowledge but action” — Herbert Spencer, 19th century English sociologist, philosopher and advocate

● ● ● **A**nd therein lies the proverbial “rub”, where lymphology, lymphatics, plus “the cause” of the fight versus lymphatic diseases (LD), including lymphedema (LE) are concerned.

Some gains have been made for LD and LE in terms of ‘awareness’, the softer and shallower sibling of “knowledge”, in terms of education. However, the elusive yet anticipated action remains relatively unfulfilled.

Edition ‘Lucky 7’ of THE day, OUR day, on the annual calendar of the ‘Lymphedema Community’ (Figure 1) has come and gone for 2022. I optimistically termed it ‘Lucky 7’ as someone who was there at that New York City café, circa autumn 2015, when/where the notion of a global day of more-than-awareness (more than idle knowledge) was born from an idea passionately discussed between individuals committed to “the cause” — the fight against lymphedema.

My optimistic thinking was that World Lymphedema Day (WLD), the idea, the name, plus the singular sea change of approach it was introduced to achieve would finally stick.

After more than two decades of these days dedicated to mere “awareness” of what is lymphedema (or lymphoedema), which received a degree of attention in

pockets of the English-speaking world (namely America, Canada, the UK, Australia and New Zealand), perhaps WLD2022 would be the turning point in what needs to be a global, united and well-communicated fight versus the chronic, progressive scourge of a disease for which there is (yet) no cure — lymphedema.

What this long-time afflictivee of LE instead witnessed was considerable continuation of messaging seeking only half measures and in an un-united cacophony of voices.

While a unified voice or, better yet, choir of voices, singing from the same choir-book, would be immensely helpful to the cause, and signify the existence of a ‘community’, it was not to be ... or at least not yet!

Please allow me to introduce myself and humour me, while I humbly propose a three-fold thought process or epiphany of why the cause, at its core, is not gaining, maintaining and sustaining the sought-after momentum to improve the lot in life of those of us living with the disease. The scenario applies across the board, whether as a female ‘lymphie’ or male ‘lympho’ afflictivee, regardless of type (primary/hereditary or secondary/acquired), stage or bodily area impacted by this disease, and/or in which part of the world one resides.

My hypothesis is articulated in the title of this piece: ‘Highest common denominator’: is it (yet) time to ‘green light’ a better ‘hook’ for “the cause” ... a perspective anew?

The perspectives or vantage points from which I draw to make my commentary are three-fold, relevant ACE (advocate, communicate, evaluate) bases, as presented below.

Advocate: “Think like someone of action, act like someone of thought”

As LymphGWG, I’ve advocated, repeatedly and successfully for more than two decades, for my own quality of life and living, despite not residing in an LE-savvy country or part of the world where lymphatics/lymphology is sufficiently taught in medical school curricula as any kind of priority, or where it is on the public health agenda or the public health system’s radar.

Communicate: “Say what you mean, mean what you say”

I communicate as an afflictivee that falls well off the world lymphedema map as a niche-within-a-niche-within-a-niche-within-a-niche case in terms of regular prospects for locating an interested, competent, compassionate (plus successfully experienced) expertise for lymphedema that is *not* secondary, *not* impacting a lymphie female body, plus *not* restricted to a more straightforward case of extremity/extremities-only affliction.

Evaluate: “doing the right things, in addition to doing things right” (discipline of Evaluation as a complement to the more omnipresent function of Audit)

As LymphoGWG (Figure 2), I’m academically trained and professionally experienced in the crafts of political science, journalism/communications, and programme evaluation.

A key tenet of this discipline — evaluation for the exercise at hand — is best and briefly articulated by Sir Winston Churchill: “However beautiful the strategy, you should occasionally look at the results.” While the well-intentioned purpose and thoughtfulness of Lymphedema Awareness Day (1994-2015) followed by World Lymphedema

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Figure 1. Within the global collective of afflicttees of lymphoedema, their caregivers and supporters play a key role. Stephen (pictured on the left) with his number one supporter and co-champion for “the cause”, i.e., the fight vs lymphoedema, Elaine McArdle (spouse); and his go-to caregiver for his complex presentation of lymphoedema, from Genoa, Italy, in the ‘Cradle of Lymphology’, Professor Corradino Campisi.

Day (2016-today) might have been beneficial, strategically, operationally and/or tactically in the war (fight) versus lymphedema, it might well be time to think and act big(ger).

Scenario – the changing context ...

Drawing on the communications storyline gems of “saying what one means plus meaning what one says”, the idea of a Lymphedema Awareness Day, as first espoused back in the mid 1990s by the pioneer and founder of the US-based National Lymphedema Network or NLN, Saskia Thiadens, did just that. At a time when lymphedema, much less its modern-English abbreviation ‘LE’, was unheard of or/and unknown, anywhere in general society, Lymphedema Awareness Day

did achieve modest limited and qualified attention gains.

Modest is used to qualify the day’s goals not to be trite or pejorative, but rather to express that, yes, in the limited areas where the day was recognised as such, ‘awareness’ was expressed. Whether that awareness was parlayed into more salient and substantive knowledge (profound education) plus attention-for-action, and for what catchment area was (and still is) less clear.

Sequing the preceding paragraph to a journalism mindset, where the golden rule is to speak in threes in an inverted pyramid-type format of storytelling, the success:

1. was limited to areas of the lymphedema world where March 6 was recognised

as ‘the day’

2. did not evidently nor significantly move the markers for attention and action from mere awareness; plus, importantly;
3. did *not* present any universally acceptable spelling of this condition (disease) about which societal awareness, knowledge and/or understanding remains relatively low and nascent.

While lymphatic diseases, notably lymphedema, are our common denominator (among the estimated approximately 300 million afflicttees worldwide), in order to advance, progress and impact the grander social psyche at a larger, wider, plus deeper scale, we need to think (and act) BIG! It is time, I argue, to address the highest common denominator of humankind, not just the population of lymphedema afflicttees.

While 300 million seems like a colossal, significant, and important population for appropriate attention, care, and treatment, the ‘message’ seems to have, so far, fallen disappointingly short. So, on a planet of approximately 8 billion humans, why not up the target population for our messaging with an educational appeal to the full body of humankind?

Yes, it is time for a concerted, unified, and convincing campaign to educate ALL of the benefits of a well-functioning lymphatic system.

Currently, as of the end of Lymphedema Awareness Month, 2022, much of the world’s total population is not yet covered by chapters and/or frameworks of the world’s only two lymphoedema umbrella organisations with truly global reach, i.e., alphabetically, the International Lymphoedema Framework (ILF) and the Lymphatic Education and Research Network or LE&RN. Unfortunately, there is no standardised spelling between the organisations established to support “the cause”; they each spell the key word differently — Lymphoedema (ILF) versus Lymphedema (LE&RN)! Small wonder, then, of confusion by the public as to what is this chronic, progressive disease.

Instead of simply pleading our case as the afflicttees of this chronic, progressive disease that deleteriously plagues a key bodily system for those unfortunate enough to have a defective, malformed,

or insufficient lymphatic system, let's loudly, consistently and convincingly also extol the benefits of well-functioning lymphatics to the remainder of the human race that is unafflicted.

Key ideas of this proposed shifting in decision-making and all-important action-taking are outlined below.

Terminology: rebrand or complementarily brand THE day, OUR day, on the annual calendar of the lymphoedema community as 'World Lymph Day' (Figure 3), thereby retaining the same acronym (WLD). Lymph instead of lymphoedema/lymphedema in WLD (for the above reason of clarity, emphasis, plus standardised English-language spelling of the disease) and to re-focus the notion that swelling of tissues all relates to lymph accumulation. Perhaps rather than 'muddying the waters' with labels like 'chronic edema/oedema', we could shift the improved focus to 'lymph' ... where, the English-language spelling is universally consistent, thus avoiding potential confusion of the general public in terms of the spelling at least.

Identity: shift the internationally accepted colour associated with "the cause" from teal to green. Green for Lymph instead of teal, a very subjective colour with myriad variations, would serve as a nexus means to link lymphology/lymphatics from medical schooling tools, such as anatomy textbooks.

Focus: Much like the straightforward 'addition by subtraction' formula was instrumental in the significantly positive shift from Lymphedema Awareness Day, which transformed into a much bigger day through subtraction of the self-limiting word 'awareness' plus expressed inclusion of 'world' to signify that any successful fight for "the cause" would need to become global, a similar outcome could be projected through subtraction of the suffix to lymph, i.e., the edema portion of the unstandardised terminology.

Elaboration — why the trifecta proposal to the 'Highest common denominator'?

As a long-time advocate plus longer-time afflictive of primary/hereditary LE, I have long witnessed that in fighting the good fight, the voiced needs of the collective (sometimes viewed with aspirational vision as a united 'community') are all-too-often meek, almost apologetic, and seemingly satisfied with mere 'awareness'



Figure 2. Lymphedema - Guerrilla Warrior General (LymphoGWG) welcomes comments at Facebook 'Lymphedema - LE Nexus Canada' where the mission tag line remains: "*Shrinking* the Lymphedema World, while *Strengthening* the Lymphedema Community ... upside & down under!"

— the significantly weaker sibling of 'education'.

Equally, in more concerted, active periods of coordinated, vocal campaigns, whether local, regional, national or even international in scope, the sender of the signal is not so much the problem or insurmountable challenge as is the receptor, or lack thereof. Sure, short-term awareness might appear, but no lasting understanding is gained for the wide-scale public at large, much less the targeted mainstream media, political and medical communities, with whom we must inevitably and tangibly connect.

With the foregoing in mind, I propose this three-part 'Perspective anew', which is a strong new tack on what has been previously tried, but directed in a sensitive, poignant plus resonant perspective — that of one whose body is blessed with properly functioning lymphatics (around 7.7 billion individuals), all the while serving to educate. The three-pronged idea serves, necessarily, as a bridge appealing to a higher common denominator. It would

also serve to unite, at least, the English-speaking world.

The ideas' elaboration is below.

Terminology: For far too long, there is a schism that sabotages any well-intended messaging, as it leaves the launch-starting blocks. I refer to the problems of spelling: what is 'edema' in US, Canada and several other portions of the world, including where English is not the first tongue, is 'oedema' in U.K., Australia, and New Zealand. The result is that lymphedema and lymphoedema present themselves to the uninitiated as two different terms. When trying to connect with, and inform and educate a readership, this immediately clouds the issue and self-sabotages "community" communications efforts.

What I propose is to shorten the day's naming or at least secondarily reference it as 'World Lymph Day'. After all, the whole English-speaking world spells the root word of the longer term as 'lymph'. A supporting reason for this shift will also be relayed under the 'Focus' section as a more positive concept for relaying exactly



Figure 3. A mock up of what the re-branded day, THE day/OUR day, for any/all afflicttees of lymphatic diseases, notably lymphedema/lymphoedema, plus their caregivers and supporters could look like.

what lymph, lymphology and lymphatics are.

Identity: This has been a curiosity of mine for some time. While the spectrum of colours used for ribbons denoting numerous causes seems endless, with overlaps bound to occur, my inquiries within Canada plus the US for the past 20 years have not met with a convincing response as to why teal was or is the colour of OUR cause.

It could be because one of the pioneers of the cause was a secondary LE afflicttee, who had survived ovarian cancer. It could be that someone simply liked the choice, which is shared also by the food allergy advocates as the colour for their cause.

Regardless, from conversations held with various doctors across a range of countries and with awareness that, unfortunately, lymphology is not a recognised medical specialty in most countries, where reliance for diagnosis often necessarily falls to other specialists with an interest in lymphatics or lymphology, I explored what would make more/most sense for representing the cause of lymph. Applying my journalism and programme evaluation academic and professional training, I very soon concluded that green was the appropriate colour to use.

Apart from a couple of doctors who could not recall the colour presented for lymph/lymphatics in anatomy textbooks at medical schools, ALL medical expertise consulted

responded, when asked, that green was (is) the colour for lymph/lymphatics that was presented along with red for oxygen-rich arteries and blue for returning blood contained in veins.

Further, from conferences attended over more than a dozen years, lymphology and compression-wear manufacturers also depicted lymph/lymphatics as green in their respective posters, too. Therefore, my proposal is that green be the accepted and globally promoted colour associated with lymph.

Focus – having presented proposals that March 6 be recognised as ‘World Lymph Day’, replete with lymph-green colour-scheme promotions, I turn to the focus of “the cause” with an eye to gaining a more attentive, widespread audience that would care about lymph and wish to have more than a passing awareness, i.e. a thoughtful, helpful education leading to action.

This is where ‘addition by subtraction’ comes into play. Much like the removal of ‘awareness’ from yesteryear’s Lymphedema Awareness Day made the projected outcomes for that day less restrained (not just awareness, but education leading to action such as more research plus support for any/all afflicttees), I propose that a similar positive effect could be achieved by another removal. My suggestion is a blunt promotion that demonstrates the

deleterious bodily impacts a healthy person with properly functioning lymphatics would face if/when he/she awoke one morning to find the body’s lymphatics had shut down.

Yikes! Welcome to OUR world and reality! This idea has been in my mind for years as a sort of ‘shock advertisement’ but has been propelled into the front-burner of my mind, again, by evident articles or campaigns that aid this conclusion. Briefly, I refer to the aesthetic and athletic appeal, or downright fascination, with the benefits of compression-wear plus compression devices in the general marketplaces of goods for ‘healthy’ people, i.e., those without compromised lymphatic systems. Given the appeal of these goods, plus the intriguing, almost carnival-type attraction they command, a campaign to illustrate why lymph/lymphatics matter, would be easily connected, possibly even piggy-backed.

For my best, tangible illustration of how I see this scenario already playing out, with its apparent applicability to “the cause”, I encourage a visit to the Facebook pages of what I term the ‘two faces’ of Mego Afek – both medical (LymphaPress home therapy system) and aesthetic/athletic (Ballancer Pro). The latter projects an improved recuperative return to normalcy; a normalcy to which lympho and lymphie types cannot, unfortunately, return.

Drawing it all together

The quote that led off this commentary piece revolved around our need for education, not for the sake of passive knowledge, alone, but rather as the impetus for informed, purposeful and thoughtful action.

I circle back to the UK, with a complementary quote to boost that same sentiment centred on action:

“Action may not always bring happiness; but there is no happiness without action”
— Benjamin Disraeli, 19th century British statesman and two-time UK prime minister

Here, dear reader, is to happiness — we could all use more of that!

Please note that throughout this editorial, the author chose to use “lymphedema”, except where the point is expressly made to show the problem of standardisation of EN-language spelling.