



Dear colleagues and friends

I am writing to confirm my willingness to run in the coming election for the Management Committee of the International League Against Epilepsy and ask for your support. In my nearly 15 years of service --mostly as representative of the Latin American Region and Epilepsy Surgery Commission- I have acquired the experience and understanding of the historical benchmarks and development, strengths and limitations of the ILAE. I believe this understanding is crucial and would enable me to work closely with our elected president to advocate strongly for efforts to improve the visibility of epilepsy, and aid in the provision of *the best care in preventing, diagnosing, treating and socially rehabilitating people with epilepsy* worldwide. I admit that I struggled with the previous phrasing and consciously refrained from quoting the mission as creating a world where no person's life is limited by epilepsy since (knowing that some might frown upon this) I believe that it being a long term goal -undoubtedly very praisable and desirable- it can distract from the more immediate needs and tasks. We have made huge advances, but we still require a lot of work expanding our educational and training opportunities, building partnerships to strengthen action and advocacy, effectively providing care and ensuring best practices, optimizing use of human and technological resources to lessen the huge treatment gap and disparities that still persist.

Perhaps a cautionary word of where I am coming from with this is needed. Contrary to the more commonly encountered experience of going from the general to the more specialized, I am a small town born Mexican Neurosurgeon trained at the Montreal Neurological Institute, who chose to go home to "pick stone" and devote my efforts to building up the first National Epilepsy Surgery Program. My reality was helping the one person with refractory epilepsy in whom we could complete the presurgical evaluation and ensure correct localization of the epileptogenic zone. Despite many initial setbacks and expected difficulties, I feel privileged to say that thanks to great collaboration we were able to help the next patient and the next ...and successfully structured a very promising program. During this build up I advocated strongly for epilepsy surgery and started collaborating with the Mexican chapter of the ILAE, and eventually with many of the new emerging Comprehensive Centers in Latin America. The urgency was primarily for the recognition of surgery as a safe and effective treatment for refractory epilepsy. However, as the collaboration expanded the reality became increasingly clearer that if the surgical treatment option was underutilized (as is regrettably also true in "better of" parts of the world) there was a huge treatment gap with a high proportion of underserved populations, mostly in the rural areas. The inequality in terms of biological, social and health coverage factors has many sources, but lack of education and training is a main one. The crude reality is that good-will and good intentions or fragmented personal efforts are not enough. So, even when I am still happiest and feel most accomplished in the OR, I have come to understand that to be a true advocate for PWE I must devote part of my time to serve in coordinating, guiding and managing tasks as offered by the aims and tasks of the ILAE.

The narrative of successes and achievements of the ILAE in the past 115 years is astounding rendering it the *de facto* leader of the international epilepsy agenda. Today and in the next term however the challenge is to "effectively land" all that generated knowledge, guidelines and definitions in place and enable the global vision to have concrete outcomes at each local level. I agree with our elected president that for the next term the focus should be on fostering the



implementation of the Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders (IGAP). We must familiarize ourselves and really comprehend the strategic objectives and global targets and follow through on the specific actions. This might however mean a drastic change of the investiture of time, resources and experience. Often I feel myself swapping between two different worlds, one in which there is precise wording, good definitions, a commitment to the more difficult cases and novel strategies, and a sense of inclusivity during my work with the ILAE and another world in the reality of my region, where there is a lack of understanding, inadequate wording, lack of even the first line antiseizure medications and basic diagnostic tools. I am unsure if we truly comprehend how much of “top down” actions we need to engage in to have an impact in the underserved populations. We know that even the best plan on paper can be worthless if local realities and needs are not regarded. In this sense:

We need to ensure collaboration and commitment of national chapters. As a chain is only as strong as its links, we have the responsibility of strengthening each chapter’s ability to have a solid structural and functional role, to identify local needs and stakeholders and to create working partnerships with governmental and non-governmental actors. In my experience as president of the Latin American region I found that many chapters restricted their involvement with the ILAE to requests for budgets for activities. The allocations of funds are always a tricky business; there is great competition for funds in today’s world and so many health initiatives worth investing in that it becomes despairingly challenging to get the balance right.

We need to ensure educational and training opportunities, that are appreciative of socio, cultural and even biological differences with clear aims, appropriate standardization and means of evaluation and follow up. Different modalities in epileptology, neurology, neurosurgery, neuropsychiatry and psychology, and nursing should be explored. Train the trainer modules have for example been very successful. It is also always tricky to find the right balance between “our own” and “theirs”. Especially in poorer resource countries we need to accept that some things are okay to be copied or translated and there is no need to “discover black gold”. The ILAE Academy and webpage resources for instance have so much potential that is often overlooked by the local chapters.

We need to strengthen our advocacy and expand partnerships between the WHO, ILAE and IBE based on solid evidence, big data and especially the welfare of PWE in mind (regardless of personal egos or other interests).

We need to foster research and innovations in epilepsy ensuring optimization of resources from the basic sciences to the clinical setting making sure that what can be done is what should be done.

I thank you for your attention and apologize for the length. I am sure that regardless of any election results we should all try to work together as a team to lessen the biopsychosocial burden of epilepsy in all our regions.

Sincerely


Mario A. Alonso Vanegas