Seizure: European Journal of Epilepsy

Taking action on climate change: testimonials and position statement from the International League Against Epilepsy Climate Change Commission

--Manuscript Draft--

Manuscript Number:	
Article Type:	Editorial
Corresponding Author:	Sanjay Sisodiya
First Author:	Angel Aledo-Serrano
Order of Authors:	Angel Aledo-Serrano
	Giulia Battaglia
	Stephen Blenkinsop
	Norman Delanty
	Hasnaa M Elbendary
	Sara Eyal
	Alla Guekht
	Medine Gulcebi Idriz Oglu, M.D.
	David C Henshall
	Michael S. Hildebrand
	Bernadette Macrohon
	Priyanka Madaan
	Janet Mifsud
	James D. Mills
	Kathryn Hodgson Neill
	Alessia Romagnolo
	Annamaria Vezzani
	Sanjay M Sisodiya

LONDON'S GLOBAL UNIVERSITY

Prof. Markus Reuber
Editor-in-chief, *Seizure*

London, January 31st, 2023

Dear Prof. Reuber,

Thank you for the invitation to submit the manuscript titled, "Taking action on climate change: testimonials and position statement from the International League Against Epilepsy Climate Change Commission" by A. Aledo-Serrano et al., to *Seizure* as editorially-reviewed material.

We are an international group of healthcare professional and research scientists who are part of the recently formed International League Against Epilepsy's Climate Change Commission (ILAE CCC). We advocate real, direct action on climate change with a specific focus on how the changing climate and associated extreme weather events will impact on individuals with epilepsy. Here, we recount the personal motivations that have led each team member to decide to take action, as well as outline the aims and goals of the ILAE CCC. We hope that this article will bring awareness to the climate issue and persuade our colleagues to foster changes within their sphere of influence.

The material presented here has not been previously published nor is it under consideration for publication elsewhere. We hereby certify that all co-authors have reviewed and approved the contents of this manuscript and that the *Seizure* requirements for authorship have been met. We also approve that there is no conflict of interest.

Sincerely yours,

Sanjay M Sisodiya MA PhD FRCP
Corresponding Author
Professor of Neurology
Department of Clinical and Experimental Epilepsy
UCL Queen Square Institute of Neurology
Director of Genomics
Epilepsy Society

Taking action on climate change: testimonials and position statement from the International League Against Epilepsy Climate Change Commission

Angel Aledo-Serrano [1] , Giulia Battaglia [2], Stephen Blenkinsop [3], Norman Delanty [4], Hasnaa M Elbendary [5], Sara Eyal [6], Alla Guekht [7], Medine I Gulcebi [8-10], David C Henshall [11,12], Michael S. Hildebrand [13,14], Bernadette Macrohon [15], Priyanka Madaan [16], Janet Mifsud [17], James D. Mills [9,10,18], Kathryn Hodgson Neill [19], Alessia Romagnolo [18], Annamaria Vezzani [20], Sanjay M Sisodiya [9,10*]

Affiliations

[1] Epilepsy Program, Neurology Department, Hospital Ruber Internacional, Madrid, Spain.
[2] Neurology Unit , IRCCS Policlinico San Donato, Piazza Malan 2, 20097 San Donato Milanese (MI), Italy.
[3] School of Engineering, Newcastle University, Newcastle upon Tyne, UK.
[4] Department of Neurology, Beaumont Hospital, School of Pharmacy and Biomedical Sciences, and FutureNeuro Research Centre, Royal College of Surgeons in Ireland, Dublin, Ireland.
[5] Clinical Genetics Department, Human Genetics and Genome Research Institute National Research Centre, Cairo, Egypt.
[6] Institute for Drug Research, School of Pharmacy, Faculty of Medicine, Hebrew University of Jerusalem, Jerusalem, Israel.
[7] Moscow Research and Clinical Center for Neuropsychiatry and Pirogov Russian National Research, Moscow, Russian Federation
[8] Department of Medical Pharmacology, Marmara University Faculty of Medicine, Istanbul, Turkey.
[9] Department of Clinical and Experimental Epilepsy, UCL Queen Square Institute of Neurology, London, UK.
[10] Chalfont Centre for Epilepsy, Chalfont St Peter, UK.
[11] Department of Physiology and Medical Physics, RCSI University of Medicine and Health Sciences, Dublin, 2, Ireland.
[12] FutureNeuro, Science Foundation Ireland Research Centre for Chronic and Rare Neurological Diseases, Royal College of Surgeons in Ireland, University of Medicine and Health Sciences, Dublin, Ireland.
[13] Epilepsy Research Centre, Department of Medicine (Austin Health), The University of Melbourne, Heidelberg, Australia.
[14] Neuroscience Group, Murdoch Children's Research Institute, Melbourne, Australia.
[15] Department of Pediatrics, Zamboanga City Medical Center, Zamboanga City, Philippines.
[16] Department of Pediatric Neurology, Amrita Institute of Medical Sciences, Faridabad, Haryana, India.
[17] Department of Clinical Pharmacology and Therapeutics, Faculty of Medicine and Surgery, University of Malta, Msida, Malta.
[18] Amsterdam UMC, Department of (Neuro)Pathology, Amsterdam Neuroscience, University of Amsterdam, Amsterdam, Netherlands.
[19] International League Against Epilepsy (ILAE), Dublin, Ireland.
[20] Department of Neuroscience, Istituto di Ricerche Farmacologiche Mario Negri IRCCS, Milan, Italy.

* Corresponding author:
Sanjay M Sisodiya
Department of Clinical and Experimental Epilepsy, UCL Queen Square Institute of Neurology, Box 29, Queen Square, London WC1N 3BG, United Kingdom, Email: s.sisodiya@ucl.ac.uk, Tel: 02034488612

E-mail addresses
Angel Aledo-Serrano, aaledo@ruberinternacional.es; Giulia Battaglia, giulia.battaglia89@gmail.com; Stephen Blenkinsop, stephen.blenkinsop@newcastle.ac.uk; Norman Delanty, normandelanty@eircom.net; Hasnaa M Elbendary, hasnaa_mohamed24@yahoo.com; Sara Eyal, sara.eyal@mail.huji.ac.il;

Alla Guekht, guekht@mail.ru; Medine I. Gulcebi, m.oglu@ucl.ac.uk;
David C Henshall, dhenshall@rcsi.ie; Michael S. Hildebrand, michael.hildebrand@unimelb.edu.au;
Bernadette Macrohon, bcchuamacrohon@gmail.com; Priyanka Madaan, doc.priyanka72@gmail.com;
Janet Mifsud, janet.mifsud@um.edu.mt; James D. Mills, james.mills@ucl.ac.uk;
Kathryn Hodgson Neill, khodgson@ilae.org; Alessia Romagnolo, a.romagnolo@amsterdamumc.nl;
Annamaria Vezzani, annamaria.vezzani@marionegri.it; Sanjay M Sisodiya, s.sisodiya@ucl.ac.uk

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Abstract

The release of the 2021 Intergovernmental Panel on Climate Change (IPCC) report makes clear that human activities have resulted in significant alterations in global climate. There is no doubt that climate change is upon us; chronic global warming has been punctuated by more frequent extreme weather events. Humanity will have to mitigate climate change and adapt to these changing conditions or face dire consequences. One under-appreciated aspect of this global crisis is its impact on healthcare, particularly people with epilepsy and temperature-sensitive seizures. As members of the inaugural International League Against Epilepsy (ILAE) Climate Change Commission (CCC), we recount the personal motivations that have led each team member to decide to take action, in the hope that our journeys as ordinary clinicians and scientists will help persuade others that they too can act to foster change within their spheres of influence.

Key words

Global warming, global crisis, seizure, neurology, epilepsy

Key points

1. Climate change is a global environmental crisis that will affect human health.
2. The Climate Change Commission of the International League Against Epilepsy (ILAE) encourages health care professional to act on climate change.
3. ILAE Climate Change Commission has developed terms of reference and an action plan for its members and the wider epilepsy research community.

Introduction

The climate emergency created by human activity threatens to have significant impacts on lives and livelihoods across the world. Climate change has already adversely affected the health of people globally; health services have been disrupted by extreme events. Further increases in temperature and associated changes in the frequency and intensity of extreme weather events will lead to an increase in ill-health and premature deaths (1), dependent on the scale of adaptation and mitigation measures (2). Climate change has prompted a coalition of 233 international health journals to issue a joint call to governments for emergency action (3). During COP26, governments made new pledges to reduce greenhouse gas emissions and adapt to the impacts of climate change (4,5). However, the pledges and actions remain insufficient to meet the commitments of limiting global warming to the target of 1.5°C above pre-industrial levels which would avoid the most severe impacts of climate change as set out in the Paris Agreement (6). The Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders, recently adopted by the 75th World Health Assembly, stated that "climate change is one of the several concurrent global environmental changes that simultaneously affect human health and neurological conditions", invited the International and National Partners of the WHO to "highlight the importance of climate change on brain health". They recommended member states to "integrate environmental determinants that are specific to brain health and neurological disorders into broader mitigation strategies for reducing the impact of climate change, including interventions and policies that promote access to clean air (ambient and household), such as the reduction of fossil fuels and the promotion of cleaner cookstoves and safe water, sanitation, and hygiene"(7). Other bodies – companies, healthcare providers, institutions – are all pledging and acting, stating their own concerns and commitments. Although the issue of climate change and its imminent consequences is gaining importance, humanity's tiny steps are falling short of the desired pace and many individuals and organizations remain disengaged.

The International League Against Epilepsy (ILAE) is the world's pre-eminent association of healthcare professionals and scientists in epilepsy working towards a world where no person's life is limited by seizures. Founded in 1909, the ILAE has national chapters in more than 150 countries and territories with over 26,000 members (8). The League has a long history of working at international level to help people with epilepsy (PWE). Primary forums to achieve this goal are ILAE Topical Commissions, trans-national groups appointed for four-year terms to carry out the work of the ILAE, and its Committees, Task Forces and Advisory Commissions (8). The ILAE's work helps set standards, educate professionals, define entities in epilepsy, and promote best practice in clinical and research settings. In 2021, the ILAE created its inaugural Climate Change Commission to advocate for action on climate change with respect to epilepsy (9).

Here, members of this new Commission recount their personal motivations in their own words as peer-to-peer stories. Our hope is that this will encourage action to combat climate change and its impacts, especially from healthcare professionals and research scientists in high income countries who are less likely to have been directly impacted by climate change.

Testimonies

Angel Aledo-Serrano, Neurologist, Madrid, Spain

From the Mediterranean semi-desert to epilepsy care, there is a short distance. I work as a clinician caring for patients with epilepsy in Madrid. However, I originally come from Murcia, a region in southern Spain and one of the most vulnerable places in Europe to desertification. Growing up in a family of farmers - Murcia has traditionally been called the "vegetable garden of Europe"- always made me aware of the power of climate and how weather-dependent we can be. Everything has changed in Murcia over the last years, when the impact of heatwaves, droughts, and floods beat the ecological, social, and economic situation. With a will to change something, I started a transition to a full plant-based diet due to the environmental implications. Nonetheless, at some point you realise

that individual efforts are never enough. In addition, as my interest progressively focused on the field of genetic epilepsies, I started to “connect the dots”. Climate awareness was never far away from my clinical practice, and the relation between extremely short-duration temperature change and seizures in conditions such as Dravet syndrome was only one example of many. Altogether, this raised the need to do *something more* and this ILAE commission could be a perfect start point.

Giulia Battaglia, neurologist, Milano, Italy

I am a neurologist with experience in the epileptology field working in Milano. During my training and career, I had the chance to live in different parts of Italy - both North and South - as well as briefly in London. The places where I lived and worked have raised my awareness about climate change, because of the different impacts it has in several contexts: I witnessed both rainfall and wildfire in Sicily, as well as an abnormally increased temperature and the lack of rain for almost five months during winter in Milano.

In addition, during my time spent at UCL in London as an Honorary Researcher in the Epilepsy Genomics team, I had the chance to see the problem from a different perspective, not just as a concerned human being but as a scientist and clinician. I began asking myself what impact could climate change have on people with chronic conditions, in particular epilepsy, and what could we do as a part of a scientific community to take action. Joining the ILAE Climate Change Commission will give me the chance to answer some of these questions.

Stephen Blenkinsop, climate scientist, Newcastle, UK

As a climate scientist for over 20 years, I have studied how our climate is changing, primarily examining how extreme rainfall has changed and could change in the future. In that time, I have witnessed the evidence for human influence on our climate become more compelling. This has come from the observations we make around the globe, from our understanding of the physical processes that drive our climate, and from the evidence provided by climate models that give us a vision of what the world

may look like if we fail to act. This has increasingly pointed to a need for action, and more hopefully we have also seen huge progress in identifying potential solutions in terms of reducing our emissions – climate change mitigation - but also ensuring that people and their environments are resilient to more extreme weather – adapting to climate change. But there is still a long way to go to avoid the worst impacts, and the time to take action is now. What has also become increasingly clear is that the solutions to a changing climate won't just come from climate scientists. It will need the combined effort of scientists across disciplines, engineers, economists, architects, educators, clinicians and many more to develop these solutions and act as advocates for change, for doing things differently. Health is an area that will be profoundly affected by climate change. Climate change will not only exacerbate existing health conditions but also create new risks in communities. The pressure that climate change could place on health care systems would also exacerbate health impacts and entrench inequalities. Working with the ILAE presents an opportunity to work with experts in the treatment of epilepsy, to assist colleagues with an enthusiasm for reducing the impact of their work on the climate, but also for understanding how climate change could affect some of the most vulnerable people in our society. Working together I believe we can contribute to the changes we need to make.

Norman Delanty, neurologist, Dublin, Ireland

I am a consultant neurologist and professor at Beaumont Hospital, Dublin, and at the FutureNeuro Research Centre at the Royal College of Surgeons in Ireland. It has been apparent to me for quite a long time that humans have over-reached themselves at the expense of the environment and of other species we share the planet with. The traditional economic growth model has taken a heavy toll. Solutions to climate change and biodiversity loss are at many levels: top down (governmental policy), bottom up (individual actions), and many levels in between (institutional, organisational, commercial). I want to play my small part in making necessary changes. I am currently taking part in a training programme called the Climate Ambassador Program run by An Taisce, the Irish National Trust. A number of my close family are also directly involved in issues related to awareness and addressing

climate change and the biodiversity crisis, e.g., my brother Greg Delanty, a poet based in Vermont has recently published a book of poems on climate change entitled “No More Time”.

Hasnaa Elbendary, clinical geneticist and researcher, Cairo, Egypt

I am a postdoctoral clinical researcher at the National Research Centre Genome Research Institute, focusing on neurogenetics, mainly on clinical evaluation of people with rare metabolic and genetic disorders. My concern about climate change comes from the temperature effects on patients. I can see in my clinic many cases with fairly controlled seizures getting worse during heat waves, leading to the need for emergency care and hospital admission. I am incredibly proud to be part of this professional organization and to be a member of the commission. I am looking forward to this new journey, to sustainably help improve the daily lives of those affected by epilepsy. I would like to raise awareness in different organizations and communities about the effect of climate change on epilepsy and how acute temperature changes can trigger seizures.

Sara Eyal, scientist, Jerusalem, Israel

I am a researcher at the Hebrew University of Jerusalem's School of Pharmacy, studying sources of variability in response to antiseizure medications in people with epilepsy. Our campus, which also hosts the main campus of Hadassah Medical Center, is surrounded by forests with two narrow roads connecting it to Jerusalem and other municipalities. Whilst we have had wildfires practically every summer since I was a student, over the past few years the heat has gotten worse, intensifying the fires and endangering hospitalised patients, medical teams, researchers, students and visitors (Figure 1). For me, this has been a wakeup call for the need to reduce our own carbon footprint while formulating means for protecting patients with epilepsy against the impact of climate change.

Medine Gulcebi, clinical pharmacologist, Istanbul, Turkey

I am a clinical pharmacologist and my main interest in epilepsy is better understanding the different responses of the people to antiseizure medications (ASMs). The main factors that impact drug response can be classified as genetic and non-genetic. What has always intrigued me about differences in drug responses between people is the alteration in serum concentration of ASMs, in other words the amount of drug patient exposed to, *via* pharmacogenetic and nongenetic factors. Besides my personal perceptions of climate change as a critical challenge for the future of our world, my first awakening about the possible impacts of climate change on epilepsy occurred whilst I read the papers about the effects of seasonal alterations on drug metabolism or the potency of ASMs (10–12). Thus, temperature found a place in my thinking as a potential factor influencing drug response.

I was delighted to join the EpilepsyClimateChange group where I started working with colleagues from different disciplines and countries, to deepen my understanding about the likely adverse consequences of climate change for people with epilepsy. Shortly after the establishment of this collaboration, the outbreak of the SARS-CoV-2 pandemic has shown us how vulnerable the world and our lives are to global threats and why we need sustainable development goals. The devastating pandemic has enlightened me about the urgency of taking action against the impacts of global challenges like climate change on health and directed me to focused efforts as a member of the ILAE Climate Change Commission.

David C Henshall, pharmacologist/neuroscientist, Dublin, Ireland

I work in Dublin, at the RCSI University of Medicine & Health Sciences and the FutureNeuro Research Centre. My interests lie in the mechanisms and treatments of the epilepsies. My motivation to try and make a difference, however small, came from several quarters. First, by reading Sanjay's article in 2019 that challenged all of us to think that climate change isn't just for climate scientists. Then, becoming aware of the disproportionate impact that laboratories such as my own have on the environment in terms of plastics waste and energy use and how small changes in how we run our labs can mitigate. Also, choosing to live more sustainably outside of work including by switching to a mainly

plant-based diet. I'm fortunate to have avoided any direct impacts of climate change but I live close to an eroding coastline where sea level changes will threaten in the coming years (Figure 1). Last, I hope to help bridge the work of this commission with the ILAE's Neurobiology Commission, working with colleagues to ensure epilepsy research carries the lowest possible climate change footprint and exploring how scientists can reduce the impact of climate change on people with epilepsy and the health professionals who care for them.

Michael S. Hildebrand, molecular geneticist, Melbourne, Australia

I come from a country with decades of successive national political leaders of all persuasions failing to act on climate change due to political self-interest and intense lobbying from the fossil fuel industry (e.g., still no Carbon Tax policy, very modest Kyoto targets) despite the highest per capita carbon emissions in the world. I have two young children born in the last decade who will pay for this lack of action by multiple generations of Australians charged with their future prosperity. Australians are already paying a disproportionately heavy price: for over three decades the southern hemisphere has had a hole in the ozone layer due to historical global chloroflurocarbon emissions leading to the highest rates of deadly melanomas in the world; in just the last 2 years we have experienced the worst bushfires and floods in the long history of challenging weather on our continent; the largest natural coral reef in the world, The Great Barrier Reef, is dying as a consequence of coral bleaching due to continual increases in sea water temperature leading to a tragic loss in biodiversity (Figure 1). Our First Nations people, their ancestors and descendants in the islands of northern Australia and the Pacific live under dire threat due to rising sea levels because of climate change. I have spent most of my scientific career studying adults and children with epilepsy, many of whom have seizures triggered by changes in body temperature (e.g., GEFS+, febrile seizures) that are directly influenced by ambient temperature.

Bernadette Macrohon, paediatric neurologist, Zamboanga, Philippines

I am a pediatric neurologist working in the southern Philippines, specifically in the Zamboanga Peninsula as well as in the surrounding islands of the provinces of Basilan, Sulu, and Tawi Tawi. Growing up in Manila, the basic concept of climate change was not discussed, nor were measures to curb it taught to us in school. During that time, we were more concerned about protecting endangered species of animals and stopping ourselves from throwing garbage out on the streets; however, as I grew up and noticed changes in our environment, I realized the importance of climate change as one big factor in the negative changes in our quality of life. For example, my childhood village is located in a valley with a large river flowing right through it. In all of my 30 years of living there, flooding occurred only among houses near the riverbanks but never did we, living about two kilometers from the river, ever experience any flood until 2009 when we had the worst flooding ever with many casualties. When I migrated to the more rural, southernmost part of the Philippines, I enjoyed the perfect balance of rain and sun until about ten years ago, when we noticed that we were having more severe storms, flooding, and landslides during the rainy season and drought during the dry season.

Throughout my 20's and 30's, I have adopted personal strategies against climate change by changing my own preferences and habits. However, I eventually realized that I need to do more to influence others to change their lifestyles and pay more attention to measures that mitigate climate change. I only realized that climate change affects health specifically among my patients when I noticed that I was getting more patients who would have seizure breakthroughs during summer/dry season when city-wide blackouts were more common, or when there were severe storms (because flooding, landslides, and unsafe sea travel hinder access to medications and healthcare). There was one day when I was cleaning out my office and I noticed many different types of promotional materials which I eventually threw out and it bothered me that pharmaceutical companies may not realize the extent to which their activities affect climate change as well. It made me understand that I should consider actions that can mitigate climate change in all my activities, not just in my personal life, but also in my professional roles. So, when I heard about climate change actions from the ILAE, I jumped right on and

I hope that I can learn more from, and contribute a bit to, this endeavour, so I can be a force of change in my community.

Priyanka Madaan, Paediatric Neurologist, Faridabad, India

I am a Pediatric Neurologist working in Northern India. During my pediatric residency in one of the most polluted cities of Northern India (and the world), I recognized the seriousness of climate change (Figure 1). Subsequently, I had an opportunity to relocate to a smaller but cleaner city for a few years. However, the extremes in temperature and humidity were also evident there. This made me consider whether or not moving to a 'better' location is a viable option. The real solution is to make the world a better place to live by efforts at individual, organizational, and community level.

I have always cared deeply about children with epilepsy and other neurological disorders. The fact that they are also affected by climate change motivated me to join the ILAE Climate Change Commission. These children are affected not only due to heat worsening epilepsy control and occurrence of temperature-sensitive seizures, but also due to their other responses to the extremes of temperature and humidity. Many children with severe epilepsy are non-verbal and cannot convey their needs, which may contribute to unexplained irritability and behavioral issues during hot and cold weather. Besides, many children with developmental and epileptic encephalopathies have co-morbid autism spectrum disorder associated with sensory issues. Temperature swings and extremes might aggravate these sensory difficulties further. Little is being done in this context, particularly in low-middle income countries. I strongly believe that striving to prevent climate change through environmental literacy can set a precedent for a better and sustainable future for all. Hence, I intend to advocate in this context for the unmet and unfelt needs (beyond seizure control) of children with epilepsy and associated neurobehavioral disorders.

Janet Mifsud, clinical pharmacologist, Valetta, Malta

Looking back I think, subconsciously, sustainability and climate change has always been an integral part of my life. Coming from a small island in the middle of the Mediterranean Sea with no natural resources except the sun, sea and rock, it was always ingrained in us that resources (especially water) need to be safeguarded. Malta has no natural rivers and in the past the only fresh water available was the limited rainwater which was stored in wells or natural reservoirs. Indeed the Knights of the Order of St John in the sixteenth century made it mandatory that every house had to have a well….a law which is still in force to this day.

Today Malta is one of the most densely populated countries in Europe (1,562 people per square kilometre) and has experienced extensive urban development in the last decades. Some experts have proposed that this will lead to significant climate change on the island due to a reduction in arable land, reduced green areas and higher buildings. A recent newspaper article by a colleague at the University of Malta Prof Charles Galdies (Newsbook, 28 January 2022) described how the Mediterranean region is one of the 'hotspots for climate change'. In fact, Malta is already experiencing higher average temperatures (an estimated 1.5°C increase on land and 0.5°C in the sea in the last 10 years) with reduced rainfall and changes in wind patterns that have led to more and stronger winds with sand from Northern Africa. This has effects on human health, agriculture output and demand for energy needed for cooling homes and offices.

Yet how does climate change affect the individual on a microlevel? What is the impact of these external climate factors on people with epilepsy? Whether the increase in both land and sea temperatures has actually led to persons with epilepsies in Malta having more seizures is to be determined: anecdotally, individual patients do assert that higher or lower than expected temperatures do cause more seizures. This needs to be studied in more detail.

There is no easy solution for an island like Malta to address sustainability and climate change issues (Figure 1). Big efforts have been made in encouraging households to have more solar energy panels, yet the heavy reliance on fossil fuel-based means of internal and international transport (since the main link to mainland Europe is by air transport) may seem to undermine such initiatives. Perhaps we

can learn from persons with epilepsy, who of necessity depend on public transport, on how to reduce our carbon footprint.

James Mills, research scientist, Utrecht, Netherlands

I am a biological researcher originally from Australia, now working in the UK and living in the Netherlands. Throughout my life, I have had the privilege to visit and live in a number of different countries. While each country is in its own way unique, one shared element that you see everywhere is the destruction of the natural environment by humans. It is a depressing realization that the destruction of the earth appears to be an increasingly common human experience (Figure 1). We are now at the point where we know that if we continue blindly down our current path, we will destroy the very thing that sustains us and every other living organism. This existential threat is both frightening and saddening. If we want to overcome this, we must all work together. I am, as many people are, frustrated by the lack of action by governments and large corporations. As an individual, I see that the best way I can make a change is by altering my own actions and attempting to influence those around me. As scientific research is a large part of my life, it is important to me to try to use this platform to raise awareness concerning the climate emergency and to make sure that the activities that I participate in are as sustainable as possible.

Kathryn Hodgson Neill, ILAE Secretariat, Dublin, Ireland

Having worked in ILAE's congress department for 18 years and witnessed the benefits that meeting up at a conference or event and the opportunity to network provide, I am in great conflict with my own personal concerns about climate change. I want to leave a better planet for my children and strive to make choices that are better for the environment and reduce my carbon footprint. We grow our own vegetables, eat less red meat, buy what we can from the zero waste shop, upcycle and take advantage of the shared car scheme in our town. But I love to travel; for my job, trips have been reduced but I believe cannot be eliminated altogether, and also to see my family and friends, as I

recently moved to a different country to where I have spent most of my life. I commend ILAE for committing to make a change and indeed taking many positive steps already, and look forward to seeing how we all tackle the challenge of travelling less

Alessia Romagnolo, PhD student, Utrecht, Netherlands

As an Italian PhD candidate living in the Netherlands for two years now, I have experienced multiple faces of climate change, from rapid shifts in temperature and flooding in Italy to abnormal heatwaves in the Netherlands. However, despite rising awareness about climate change and sustainability, I've seen inaction in the face of worrying events. As a basic research scientist, I have come to realize how my job impacts on climate change, given the massive amount of daily plastic waste from research labs. Furthermore, I started exploring how big the implications of climate change are for people with epilepsy and how we can try to help and try to mitigate the impact of climate change, for instance by acting on research sustainability. When the opportunity arose to investigate what researchers and clinicians can do towards these aims via the ILAE Climate Change Commission, I thought it was the best way to take action and contribute to helping others.

Annamaria Vezzani, research scientist, Milano, Italy

I am head of the Laboratory of Experimental Neurology at the Mario Negri Institute for Pharmacological Research in Milano. The main research focus of my studies is on molecular mechanisms involved in the pathogenesis of seizures with special interest in developing new treatments and disease biomarkers. My interest in climate change and its impact on epilepsy arises from my preclinical research background. It is well known that hyperthermia, and extreme changes in core temperature, may precipitate seizures and exacerbate epileptic activity by decreasing seizure threshold. Moreover, temperature changes may affect neuronal function and excitability. Seasonal influences also affect seizure manifestation and their response to antiseizure medications. I became aware that the world is suffering from serious climate change and that there is an urgent need to

elaborate and put in motion rescue strategies to arrest the deleterious consequences of carbon emission and the waste of non-biodegradable material. I was struck, among the various consequences of climate changes, by the drought of the longest river we have in Italy, the Po river, and the dramatic consequences for human life and environment (Figure 1). This is why I am interested in contributing to the work of the Commission. I think that it is an ideal platform to merge complementary preclinical and clinical expertise for better understanding the potential impact of climate changes on persons with epilepsy, and for promoting awareness, and helping to find solutions and foster further research in the field.

Sanjay Sisodiya, adult neurologist, London, UK

I am an adult academic clinical neurologist working in the UK. In clinic, I see many people with complex epilepsies with multiple comorbidities. Most of these people have kindly agreed over many years to join in our research projects, especially genetic studies that have increasing revealed monogenic causes for their conditions. At a personal level, I have had a long interest in environmental issues and sustainability. My personal concerns about the future of our world and my professional focus on the health and wellbeing of the people with epilepsy that I see in clinic converged one day over the emergency issue of climate change, as I heard carers of people with fever- and temperature-sensitive genetic epilepsies report that seizures and lethargy had markedly worsened during one of the heatwaves we have experienced in northern Europe over the last few years. The link suddenly seemed obvious and important to me, and grew rapidly with an exploration of the literature on climate and health. But I was uncertain how eccentric this view might be, and so contacted longstanding, trusted senior colleagues with a very tentative email. Fortunately, the response to that and many subsequent contacts with colleagues around the world has been almost always uniformly supportive: most people have shared their own concerns, or had the same realization.

The strength of responses I received have led to the formation of the loose collaboration, EpilepsyClimateChange, which held its first virtual conference on November 25th 2021 (recorded talks

available at https://epilepsysociety.org.uk/climatechange/epicc-video#epicc-conf-video), more than two years after it had been planned, postponed by the pandemic with all its serious and deadly consequences, and with its demonstration to us all of both the importance of global collaboration to tackle global health threats and the possibility of other ways of working. Subsequently, the ILAE decided to set up the Climate Change Commission, a bold statement of intent; other organisations have taken similar initiatives. These are not just token steps: when serious institutions espouse such initiatives, they raise awareness and declare their purpose, and can be held accountable for their actions, or lack of them.

I have learnt much about the climate emergency since the connection happened for me between personal concerns and professional life. There are some remarkable initiatives local and global organisations, nations, and individuals are taking, often with deep passion and commitment. Much of what I have learnt has generated in me what is broadly termed 'climate anxiety'. A sober examination of the data is frightening. It can be paralysing. But strategies to deal with such psychological responses are also emerging, amongst which is increasingly recognized to be, for example, the value of taking action. This is why I now spend time on climate and epilepsy. I would rather keep working on the problem of drug resistance in epilepsy, an area of long-term interest, and on the value of genomics in epilepsy, and many other habitual daily interests. But I cannot ignore what is happening around us, and, accepting the climate emergency as probably the biggest challenge life on earth is facing, I feel compelled to act: if we want to preserve the life we want, we cannot keep living the life that we are (Figure 1). What gives me most hope is the equal commitment and passion of professional colleagues who feel the same concerns and the same force to act – partly why we as members of the Climate Change Commission decided to write this piece. We need to be part of the solution, and not the part of the problem, nor idle bystanders to the greatest challenge of our times.

Taking action – the next steps

Storytelling is an ancient human pursuit of value recognized across domains of human activity from the battlefield to the nursery. Storytelling has acquired renewed value in the climate emergency, but with added urgency, and changing perspectives (13) . It can help to engage and educate, but must also promote action. Members of the ILAE Climate Change Commission are unanimous that their tenure has to be one of action and progress, and not limited to talk. It has developed Terms of Reference (Box 1) and an action plan for each of its three task forces (Box 2), and due course will be judged by its achievements.

There are overarching groupings that are making important contributions in this area, such as The World Health Organization, The Global Climate and Health Alliance, Healthcare without Harm Global Network, and the UK Health Alliance on Climate Change (UKHACC) (14–17). Other disease-specific organisations are moving in the same unified direction, with some having made important progress already (Table 1) (18–25).

We are a group of ordinary clinicians and scientists. We have decided to join many others around the world involved in healthcare to take action on climate change, and do what we can within our own spheres of influence. We hope that the simple descriptions of our own journeys to action will help encourage others, especially those less familiar with these issues or feeling that they as individuals cannot achieve much. We need to act both as individuals and within organisations: together we can help mitigate and adapt to the greatest challenge of our times – for those for whom we care, for ourselves and the generations to come.

Acknowledgments

We would like to thank the photographers, Kurt Arrigo, Catherine Lane, Natalia Erenburg, and Gary Cranitch and our authors, Annamaria Vezzani, Bernadette Macrohon, Sanjay Sisodiya, Janet Mifsud, Sara Eyal, David C Henshall, Michael Hildebrand, and Priyanka Madaan for the permission to use their valuable photos.

Author Contributions

Sanjay M Sisodiya, Angel Aledo-Serrano, Giulia Battaglia, Stephen Blenkinsop, Norman Delanty, Hasnaa M Elbendary, Sara Eyal, Alla Guekht, Medine I Gulcebi, David C Henshall, Michael S. Hildebrand, Bernadette Macrohon, Priyanka Madaan, Janet Mifsud, James D. Mills, Kathryn Hodgson Neill, Alessia Romagnolo, and Annamaria Vezzani wrote their personal testimonies, wrote the original draft, and reviewed the manuscript. Sanjay M Sisodiya, James D. Mills, Medine I Gulcebi, and Priyanka Madaan edited the manuscript. Sanjay Sisodiya conceptualised the manuscript.

Conflict of Interest

None of the authors has any conflict of interest to disclose.

Ethical Publication Statement

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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Box 1: Terms of Reference for the ILAE Climate Change Commission

As the ILAE recognises that climate change poses a significant threat to the lives and wellbeing of people with epilepsy and to the work of professionals in the field, the CCC undertakes to:

- Ensure that as a responsible organization, ILAE quantifies and understands its entire direct and indirect greenhouse gas emissions (Scopes 1-3), and commits to reducing Scope 1 and 2 emissions to net zero by 2030, and Scope 3 by 2035, ideally with external certification.
- Promote and establish sustainable practices across all ILAE activities, including its own operation, meetings, congress venues (to the extent ILAE has power to do so), publications, sourcing and recommendations (e.g of particular clinical or research practices in epilepsy).
- Raise awareness amongst, and educate, ILAE membership about the impact of climate change (including through the promotion of research, knowledge and understanding) on people with epilepsy and epilepsy professionals, and of their own professional contributions to climate change: achieving climate literacy.
- Demonstrate leadership in this field and to engage with, and influence, other organisations and colleagues to achieve the same ends.
- Elaborate strategies and policies for adaptation and mitigation and best practice according to these terms.

Box 2: Plans of action for ILAE Climate Change Commission Task Forces

Task Force 1: ILAE Sustainability

Priority Action Plans

1. To analyse annual financial statements to confirm ILAE investments meet strict Environmental, Social and Governance (ESG) criteria.
2. To promote engagement of the epilepsy community with regard to climate change by driving ILAE support of education fora and annual community awareness activities.

3. To generate data to support implementation of sustainable catering and materials for, and travel to, ILAE congresses.
4. To encourage the continued transition of the ILAE stable of international scientific journals to sustainable electronic-only versions.

Task Force 2: Sustainability Engagement

Priority Action Plans

1. To engage with and learn from other organizations on climate change initiatives.
2. To spread information on sustainable activities and initiatives to ILAE members and other organizations (in liaison with Task Force 1)
3. To develop strategies (such as providing accessible information) for increasing awareness on the effects of climate change and measures to mitigate these in our practice (in liaison with Task Force 3).

Task Force 3: Research Sustainability

Priority Action Plans

1. To conduct a survey among preclinical and clinical researchers on their awareness and actions taken in their research practices to mitigate the impact of their research activities on climate change.
2. To perform a systematic review and/or meta-analysis of studies on the impact of climate change on epilepsy.
3. To determine the impact of epilepsy care telemedicine vs in-person consultation on climate change.
4. Propose preclinical/clinical research approaches that may help to better understand the impact of climate change on epilepsy.

Table 1: Examples of organizations taking action on climate change

Sno.	Organisation	Focus	Membership spread	Sustainability and climate initiatives and actions
1.	World Health Organization(14)	Health	Global	○COP26 Health Programme ○Climate Resilient Health systems Initiative ○Special initiative on Climate change and Health in small Island Developing states
2.	The Global Climate and Health Alliance(15)	Climate change and Public health	Global	Several initiatives • WHO-Civil Society Working Group to Advance Action on Climate and Health • Climate-Health Africa Network for Collaboration and Engagement • Call to action on Climate and Health
3.	Healthcare without harm Global Network(16)	Health	Global	○ Leads Global Green and Healthy Hospitals, a worldwide network of hospitals and health systems with more than 1500 members in 75 countries.
4.	The UK Health Alliance on Climate Change (UKHACC) (17)	Health	Alliance of primarily UK-based organizations	○In Conversation programme with a series of virtual roundtable lunchtime sessions for members
5.	American College of Physicians(18)	Internal medicine	Global	○ Climate change and Health: A position paper of the American College of Physicians ○ Climate change Toolkit
6.	American Heart Association(19)	Cardiology	Global	Guidance to reduce the cardiovascular burden of ambient air pollutants: A policy statement from AHA (2020)
7.	American Academy of Pediatrics(20)	Pediatrics	Global	Global climate change and children's health policy statement (2015)
8.	American Psychiatric Association(21)	Psychiatry	Global	Position Statement on Climate Change (2017)
9.	American College of Obstetricians and Gynecologists(22)	Obstetrics and Gynecology	Global	Addressing Climate Change Position Statement (2016)
10.	Asthma and Allergy Foundation of America (23)	Asthma	Global	Policy statements, comments and letters of support regarding public policies
11.	American Psychological Association (24)	Psychological health	Global	○APA Task Force on Climate Change
12	European Society for Medical Oncology(25)	Medical Oncology		• 'A train to ESMO' for the climate initiative 2019 encouraging all the oncology community to take a train rather than the airplane to reach main events in the field across Europe • ESMO climate change taskforce

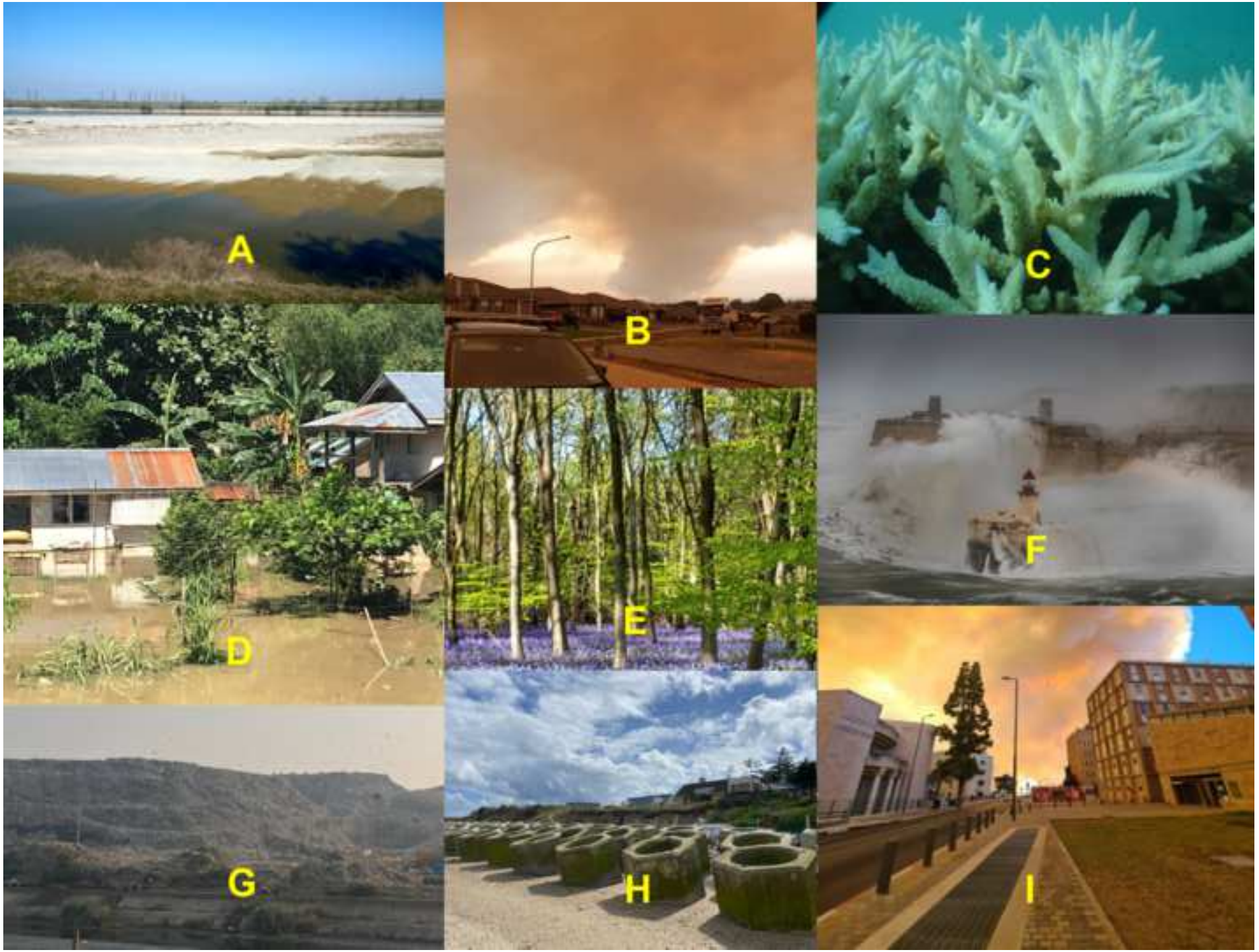
12.	The Lancet (26)	Medical journal	Global	○2015 Lancet Commission on Health and Climate Change and subsequently, annual publication of The Lancet Countdown on health and climate change

Figure Legend

Figure 1. Photos from the countries of commission members involved in their own stories for climate change: **A**. The Po river, the longest river in Italy, drying in a heatwave in 2022; **B.** Bushfire in Australia (2019/2020); **C**. Coral bleaching due to continual increases in sea water temperature; by photographer Gary Cranitch, courtesy of Great Barrier Reef Foundation, Australia; **D**. Rice paddies and some communities submerged in flood, Philippines; **E**. Bluebells flowering early, southern UK; **F.** Twenty meter high waves hitting Fort Ricasoli, Grand Harbour, by photographer Kurt Arrigo, Malta (2019); **G.** Overflowing Ghazipur landfill, a mountain of garbage in Delhi, India- spread over more than 70 acres with raptors hovering over it is a serious public health concern and a site for frequent landfill fires in heatwaves; H. Concrete barriers to prevent erosion aggravated by climate change, Dublin, Ireland; I. Wildfire near the Ein Kerem Campus of the Hebrew University/Hadassah Medical Center, by Natalia Erenburg, Israel (2021).

Figure

Click here to access/download;Figure;Figure 1.png



Conflict of Interest

None of the authors has any conflict of interest to disclose.