All-Party Parliamentary Group onAppg Malaria and Neglected Tropical Diseases

Newsletter February 2023

MESSAGE FROM OUR CHAIR

Dear Members and Supporters of the APPG on Malaria and NTDs,

It has been a busy few months for our All-Party Parliamentary Group. With the announcement of the UK's contribution to the Global Fund to Fight AIDS, Tuberculosis and Malaria, the publication of the World Health Organization's World Malaria Report 2022, and World NTD Day, we have had a packed end of 2022 and start to 2023.

At the end of the year, we welcomed two important appointments that will have significant impact on our work. Firstly, Dr Ibrahima Socé Fall became the new Director of the WHO's Department of Control of NTDs. A public health scholar, global health leader, and infectious diseases epidemiologist, Dr Socé Fall has vast experience in the WHO having joined the Organization in 2003. The APPG was able to hear from him in a video address at our event on World NTD Day in January, where he framed the challenges we face in the control and elimination of NTDs, and argued powerfully for ensuring that communities are at the heart of our collective response. We look forward to working with him in making the important case for shared resources, expertise, skills, and investment in NTDs.

We also welcomed Andrew Mitchell to his new role as Minister for Development – a promising appointment given Andrew's long-standing commitment to the fight to end malaria and NTDs. I have already had the opportunity to meet with Andrew, alongside the Chairs of the APPGs on Global Tuberculosis and HIV and AIDS, to discuss the Global Fund, and how we can work together over the coming months. We look forward to working with him to ensure these diseases are discussed alongside Government priorities of ending preventable deaths, pandemic preparedness, women and girls, and health systems strengthening.

One of Andrew's first decisions as Minister for Development was the long-awaited announcement of the UK's contribution of £1 billion to the Global Fund. Over the past year, the APPG has been calling for a bold and ambitious funding commitment from the UK, and we continued this right up until the pledge with my Conservative APPG colleagues James Sunderland and Derek Thomas writing in <u>The Times</u> to make the case for renewed support.

The commitment of £1 billion was a welcome pledge and a significant sum at a time of great need at home and abroad. We were particularly pleased to see continued support in the pledge statement for investment in R&D, including through our world-leading Product Development Partnerships. However, we are concerned about the reduction of the UK's level of spending from the Sixth Replenishment – the first time in the Global Fund's 20-year history that the UK has reduced its allocation, leaving us out of step with G7 partners such as the US and Germany, who increased their funding commitments. Recognising what a critical time this is for malaria, and the impact this will have on the lives of the millions of people around the world who bear the brunt of the disease, the APPG hopes to work constructively with Ministers at the FCDO to ensure we can return to a full contribution to this vital Fund as soon as is possible, and can retain our place as a global leader in tackling malaria.

This need to redouble our efforts on malaria control, elimination, and eradication was made clear in the findings of the WHO's World Malaria Report for 2022, published in December. There was some cause for hope in the report – despite the continued impact of the COVID-19 pandemic, endemic countries largely held the line against further setbacks to malaria prevention, testing and treatment services, with an estimated 619,000 malaria deaths globally in 2021 compared to 625,000 in the first year of the pandemic, and malaria cases rising but at a slower rate than 2019 to 2020.

The findings show, however, that we remain at a critical juncture in the fight against malaria – findings which were reinforced in a meeting the APPG held with Members of Uganda's Parliament who outlined to us the reality on the ground and in their constituencies. Colliding crises – including conflict, climate change, restricted funding, rising biological threats, incomplete data collection, and a decline in the effectiveness of core disease-cutting tools – threaten the global response. To coincide with the report, I co-hosted an event in Parliament with Malaria No More UK to inform Parliamentarians about the findings of the report and the implications for the UK's commitment to tackling malaria. Our discussions focused on the need for new and continued investments in R&D, innovation, and scientific leadership which are crucial in our efforts to reduce the malaria burden, support health system strengthening, and ensure no one is left behind. Our APPG will continue to call for long-term investment in malaria research and innovation, and support for our amazing and innovative regional academic and research institutions, including Product Development Partnerships.

On NTDs, we have seen some positive news recently. In September, Malawi successfully eliminated trachoma as a public health issue – the first country in southern Africa, and the first country funded by The Queen Elizabeth Diamond Jubilee Trust, to achieve this milestone. However, there are still considerable challenges. October's <u>Times article</u> on schistosomiasis in Zanzibar, for example, laid bare the stark reality of the impact of reductions in UK aid, with cases again rising in a region which had been on the brink of eliminating the disease. Our task as an APPG is clear – we must continue to raise awareness in the UK Parliament of these neglected diseases, and work with partners to make the case for strong and sustainable investment.

This year's World NTD Day was a key moment for us to do this. The theme for the day focused on the need for sustainable financing for NTDs – with a lack of resources, intensified by the COVID-19 pandemic, seen as a significant barrier to the control of these diseases. To mark the day, I sponsored a week-long exhibition in the Upper Waiting Hall in Parliament, featuring some incredible photos, artwork, videos, and textiles from some amazing NTD projects and organisations, all united in their dedication to working towards ending these devastating diseases. As part of the exhibition, we showcased winning and shortlisted posters from a competition run for eight- to 16-year-olds by SCI Foundation. Art has a real power to shed light on issues that some people may not be aware of, and this competition helped to shine a spotlight on NTDs in a different and creative way. I am passionate about engaging with our young people on science and innovation, and enjoyed meeting the winners and seeing some of the shortlisted entries.

Importantly, this quarter, we have been able to hear directly from those affected by these devastating diseases. At the exhibition's opening ceremony, I met Dr Subodha Handhi Galahitiyawa who bravely and passionately shared a personal account of living with leprosy, and the impact of the daily discrimination

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et's end malaria!

#ZeroMalaria

she faced. Her words were incredibly compelling – a stark reminder of the daily struggle these diseases have on individual lives. We also heard powerful testimony from noma survivors Fidel Strub and Mulikat Okanlawon at a roundtable discussion on noma. I first learnt about noma in 2021 when I met with researchers from York University and the Liverpool School of Tropical Medicine, and am pleased we have been able to raise awareness of this disease again and join the call for it to be included in the WHO's official list of NTDs. Fidel and Mulikat have dedicated their lives to speaking for the neglected and voiceless victims of this horrific disease, and I am honoured we were able to welcome them into our discussions and provide a platform for their powerful words. Both Fidel and Mulikat, Subodha, and Serena Mukhi – a malaria survivor who spoke at our World Malaria Report event – raised the importance of including affected people in every level of research into defeating these diseases; a theme we will try to incorporate into our work going forward.

Excitingly, for the first time since the COVID-19 pandemic, we have also been able to open up some of our events to our wider network of supporters, which is a fantastic step, and we have been delighted to meet new and old faces at our events on noma and World NTD Day. The knowledge and experience we have in our supporter group is incredibly wide-ranging and a very welcome resource for our Parliamentarians. We are always open to new suggestions as to what we should focus our work on – do get in touch with our Coordinator, Martha, with any ideas. Her details are at the end of the newsletter.

So, a busy few months, but lots more work to do – and I look forward to redoubling our efforts in the months ahead. As a Group, as always, we will continue to work as hard as we can towards building the momentum needed to fight these deadly diseases.

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Catherine West

MP for Hornsey and Wood Green and Chair of the APPG on Malaria and NTDs

Events

WHO World Malaria Report 2022

Each year, the release of the World Malaria Report offers the opportunity to reflect on the current state of malaria, and to assess what more can be done to accelerate the global fight for malaria eradication. To coincide with the launch of the report, the APPG co-hosted an event in Parliament together with Malaria No More UK to raise the profile of malaria and to update Parliamentarians on the latest assessment of trends in malaria control and elimination, and the challenges that we continue to face. The event also provided an opportunity to get together as a wider community to discuss latest innovations and tools in the pipeline, and what support is needed so we can continue together to make the case for continued UK action.

Our Chair, Catherine West MP, hosted the event, with Rt Hon Andrew Mitchell MP providing the keynote speech – in which he reaffirmed the Government's commitment to global health and ending preventable deaths – and Dr Alastair Robb, a senior adviser from the WHO, presenting the report findings with a focus across response, risk, resilience, and research.

There was also a panel discussion with Professor Azra Ghani, Chair in Infectious Disease Epidemiology at Imperial College London, and Serena Mukhi, a youth ambassador for Malaria No More UK and a graduate of the London School of Economics. Serena was diagnosed with a severe case of malaria when she was two years old living in Nigeria, and passionately highlighted the importance of awareness and education around malaria prevention and treatment. The panel discussion centred around what is needed to get back on track to reach global malaria targets, and how we can support the development and strategic targeting of new tools, and our critical and innovative research and development work, that is so vital in the fight against this devastating disease. As WHO Director-General, Dr Tedros Adhanom Ghebreyesus, said on launching the report, "We face many challenges, but there are many reasons for hope. By strengthening the response, understanding and mitigating the risks, building resilience and accelerating research, there is every reason to dream of a malaria-free future."



Panel discussion with Dr Alastair Rood, Professor Azra Ghani and Catherine West Mi at the UK Parliamentary launch of the WHO World Malaria Report 2022.



Noma survivor and advocate, Fidel Strub, speaks at a roundtable event in Parliament

Noma

In January, the APPG co-hosted a panel discussion with MSF, the University of York's Centre for Applied Human Rights, and York Law School, on noma, titled 'Through the eyes of survivors and scientific evidence, lifting the neglect from a neglected tropical disease'. The APPG has been involved with the noma campaign since 2021, when our Chair, Catherine West MP, met with researchers from the University of York and the Liverpool School of Tropical Medicine to discuss the neglected profile of the disease.

Noma is a neglected disease which mainly affects children under the age of seven living in conditions of extreme poverty. The disease has a staggering untreated mortality rate of 90 per cent in the first two weeks. Our roundtable brought together advocates, scholars, and humanitarian practitioners to raise awareness in the UK about noma and the ongoing campaign for its formal recognition by the WHO as an NTD. We heard from noma survivors and advocates, Fidel Strub and Mulikat Okanlawon, who shared their incredibly powerful personal stories of living with noma, the stigma and social impact of the disease, and the importance of awareness and education. We were also joined by Dr Mark Sherlock and Claire Jeantet from MSF and Dr Ioana Cismas from the University of York's Centre for Applied Human Rights, who spoke about the importance of acknowledging noma as an NTD and embracing a human rights-based approach to the disease. The event included the screening of Inediz's award-winning short documentary 'Surviving Noma' which offers a glimpse into survivors' lives and documents their voice and their stories. You can see this powerful short film here.

Following the meeting, the APPG wrote to the Foreign Secretary and Minister for Development to bring renewed attention to noma, and to call for UK support for the inclusion of noma in the WHO list of NTDs. It is hoped that recognition of noma as an NTD will bring the required attention to the disease, including funding for research.

NTD Exhibition

To coincide with World NTD Day on 30 January, our Chair, Catherine West MP sponsored a week-long exhibition in Parliament to raise awareness of NTDs across MPs and Peers, through providing an understanding of the different NTDs and their impact, and highlighting successful projects working to tackle them.

Working with APPG partners, including the UK Coalition against NTDs, the exhibition featured images and video across the diseases and showcased some of the successful UK-funded projects and programmes – including the National Institute for Health and Care Research-funded ECLIPSE and REDRESS projects for skin stigmatising NTDs. There were also some pieces from loaned art collections and exhibitions by social engaged artists – for example, a scabies wearable experiential garment which was made for a public education event by textile artists, and art submissions from the Global Youth NTD Storytelling Festival led by Uniting to Combat NTDs – which helped give an understanding of those living in endemic regions and their experiences with NTDs.



and Dr Charles Mowbray at the NTD exhibition in Parliament.

The exhibition was launched with an opening ceremony which included a powerful video address from the new Director of the WHO's Department of Control of NTDs, Dr Socé Fall, who provided a WHO perspective on the challenges we face together to beat NTDs and a call to ensure communities are at the heart of our collective response. Professor Getnet Tadele, from the Department of Sociology at Addis Ababa University, gave an insightful presentation by video on the social sciences for stigmatising skin conditions and the societal barriers to treatment, including stigma and discrimination. And Dr Charles Mowbray, Discovery Director at DND*i*, spoke about the need for innovation and research into new tools for the prevention, diagnosis, and treatment of diseases of poverty, and made the case for ensuring that new tools are made available to everyone who needs them, at the right time and in the right way. We were also honoured to be joined by Dr Subodha Handhi Galahitiyawa who spoke about her experience of living with leprosy, the importance of awareness and education, and the need to include affected people in every level of research into NTDs.

In addition, winning and shortlisted posters from a competition run for eight- to 16-year-olds by SCI Foundation were featured in the exhibition and three young artists joined the opening ceremony to be presented with their certificates from Chair, Catherine West MP, Vice-Chair, Virendra Sharma MP, and Dr Wendy Harrison, CEO of SCI Foundation.



panel from the exhibition in Parliament for World NTD Day

DNDi roundtable on new technologies for old diseases

Also coinciding with World NTD Day, our Chair, Catherine West MP, and Vice-Chair, Lord Trees, joined a breakfast roundtable convened by DND*i* and chaired by Professor Lucy Chappell, Chief Scientific Adviser at the Department of Health and Social Care. The roundtable focused on how we can apply Artificial Intelligence (AI) to help discover and develop new treatments and diagnostics for diseases which are neglected and which often do not feel the benefits of new technologies until much later.

The use of AI is already allowing collaborations which are improving the efficiency of life-saving discovery research into new treatments for global health, in particular for NTDs. Promising partnerships with AI companies are already taking place, for example to use molecule structure prediction algorithms to find compounds against leishmaniasis and Chagas, or to identify repurposed drugs to treat dengue. Dr Charles Mowbray, Discovery Director at DND*i*, described the work of DND*i* in partnering with UK AI companies to use some of the new technologies to speed up drug discovery and development for diseases such as dengue and leishmaniasis, work which is all the more important given the climate sensitive nature of these diseases.

Questions for discussion at the roundtable included how can AI and new technology contribute to the fight against NTDs, what are the barriers to implementing new technologies and AI for neglected diseases and how can we overcome them, and how can UK scientists and the UK Government contribute to this work and enable and support such collaborations.



Baroness Shields (Benevolent Al), Professor Lucy Chappell (DHSC), Dr Charles Mowbray and Dr Craig Tipple (DND/), and Dr Dirk Mueller (FCDO).

Delegation from the Parliament of Uganda

The APPG was honoured to host a productive roundtable discussion with a delegation of MPs from the Parliament of Uganda, together with members of the Uganda Parliamentary Forum on Malaria (UPFM) and the Uganda UK Health Alliance. The roundtable provided a chance to build and strengthen relationships with Parliamentarians working on global health in Uganda, and an opportunity to share best practice around political engagement on tackling malaria as well as to hear an update on challenges to malaria control and elimination across Uganda, and the reality of the situation on the ground.

Hon Fred Opolot MP provided opening remarks on behalf of the Speaker of the Parliament of Uganda and Hon Dr Timothy Batuwa MP opened the discussions as Chair of UPFM. UPFM provides a platform for Uganda's MPs to advocate for and champion funding for malaria, and to generate visibility and provide leadership to the control and elimination of malaria in Uganda.

We heard how the entire population of Uganda is at risk of malaria, accounting for 30 to 50 per cent of out-patients' consultations and costing a family an average of three to nine per cent of annual household income per episode. The WHO World Malaria Report 2022 showed that Uganda accounts for 5.1 per cent of all malaria cases globally and 3.2 per cent of deaths, with 19,663 deaths recorded in 2021. The case burden remains nearly 10 per cent higher than it was in 2015.

Dr Batuwa outlined how the Ministry of Health and partners have been working tirelessly to reduce the malaria burden but that there have been real setbacks to progress, exacerbated by the COVID-19 pandemic. He reinforced that UPFM is deeply committed to exploring all opportunities for reducing the burden of malaria in Uganda, particularly among the most vulnerable groups such as children and pregnant mothers. He also highlighted the need to increase support and investment in innovative vector control and diagnostic tools, including in the research and development of promising tools and vaccines. Dr Batuwa also discussed the need for renewed bilateral support from the UK, and expressed concern on the correlation between the ending of UK bilateral malaria programming and the rise in cases and mortality in Uganda. We have committed to raising the situation in Uganda with the Foreign Secretary and look forward to building on our relationship with UPFM and supporting UPFM and Uganda in its malaria control and elimination efforts.



Tan Dhesi MP, Lord Trees and Baroness Sugg at the roundtable with a delegation from the Parliament of Uganda and the Uganda Parliamentary Forum on Malaria.

Parliamentary Activity

ODA debate

To mark the publication of the WHO World Malaria Report 2022, our Vice-Chair, Baroness Sugg, spoke in a House of Lords debate on overseas development assistance (ODA), highlighting the findings of the report, and stressing it's not too late to turn the tide and get us back on track to ending malaria by working together with the rest of the world and alongside key partners such as the Global Fund and GAVI.

"Like many aspects of global health, progress has stalled since the COVID-19 pandemic, but it is not too late to turn the tide and get us back on track. For us to succeed, the UK needs to play its part in investing in global health. We need a thriving R&D pipeline with enough funding to accelerate next-generation tool development; and we need to ensure increased funding to create resilient health systems, so that life-saving tools can reach the communities which need them, including through the Global Fund, GAVI, the Vaccine Alliance and our bilateral programmes. The UK has the diplomatic, scientific and financial muscle, still, that we need to get the fight back on track. I hope my noble friend the Minister can reassure me that we will continue our funding and show strong political leadership to help get us back on track."

You can access the debate in full here.

Flooding in Pakistan

A rapid upsurge in reported malaria and dengue fever cases has been observed in Pakistan after an abnormal monsoon rainfall and unprecedented flooding that began in mid-June 2022. In December, our Chair, Catherine West MP laid a written parliamentary question about UK support to Pakistan in response to the floods and the rise of vector-borne diseases including malaria, dengue fever, chikungunya, and leishmaniasis. FCDO Parliamentary Under Secretary of State, Leo Docherty MP, responded providing some assurances that, recognising the impact that the floods are having on vector-borne diseases, UK assistance is targeting sectors that will mitigate and reduce transmission, including shelter, water and sanitation, health, and nutrition.

You can see the question and response in full here.

Articles

In November, ahead of the UK's pledge to the Global Fund, our Vice-Chair, James Sunderland MP, and Member, Derek Thomas MP, made the case in The Times newspaper for renewing our support to the Fund and the need to protect foreign aid to ensure millions of people don't suffer.

"As devastating as the pandemic was, it could have been worse had it not been for the decades of investment in global health that played a vital role in reinforcing vulnerable health systems and reducing the horrific fallout from the pandemic.

This is why organisations like the Global Fund are so critical. It was one of the

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unsung heroes of the pandemic, and now forms one of the cornerstones in our global efforts to ensure we are better prepared and better equipped to reduce the threat from future pandemics.

While the Global Fund has been able to save 50 million lives since its inception across the three diseases, all of this progress could be at risk if the UK does not step up to the challenge. As vice-chairman of the all-party parliamentary group on malaria and neglected tropical diseases, I (James Sunderland) have seen first-hand the devastating impact that diseases like malaria continue to have on communities, including when I visited a health centre on the outskirts of Kigali, Rwanda, earlier this year. We just cannot risk losing any more lives to a disease that we know is entirely preventable, treatable and beatable."

You can read the article in full here (paywall).



Catherine West MP with Rt Hon Andrew Mitchell MP, Minister for Development, and the Co-Chairs of the APPGs on Global Tuberculosis and HIV and AIDS.

Statements

In November, the UK committed £1 billion to the Global Fund. The APPG welcomed the contribution but expressed concern about the impact on malaria eradication of a reduction in UK spending. You can read our statement in full below:

"The APPG on Malaria and Neglected Tropical Diseases welcomes the Government's announcement to pledge £1 billion over the next three years, as part of the crucial Seventh Replenishment of the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund).

This funding comes at a critical time in the global fight against these devastating diseases. Despite tremendous progress over the last two decades, colliding crises – including conflict, climate change, the COVID-19 pandemic, and other global health challenges – threaten to knock us backwards. Malaria deaths have now risen to the highest rate in nearly a decade, with half of the world's population living under the shadow of the disease.

We are relieved to see the Government's continued support for the Global Fund which has reduced deaths from malaria by 26 per cent since the Fund was founded in 2002 and which, in 2021 alone, distributed over 133 million mosquito nets and tested over 280 million suspected malaria cases. We also welcome the Government's decision to continue to invest in research and development through world-leading Product Development Partnerships, and to introduce a UK-Global Fund performance agreement, putting health system strengthening, health equity, gender, and human rights at the very core of the Global Fund's work.

However, we are concerned that the UK has not been able to maintain or increase its level of spending to the Global Fund from the Sixth Replenishment, and in fact has decreased its contribution by 29 per cent. This will have a real impact on the millions of people around the world who bear the brunt of malaria, and threatens to push us further off track in our global eradication goals. We hope to work constructively with the Minister for Development to ensure we can return to a full contribution to this vital Fund as soon as is possible, and can retain our place as a global leader in tackling malaria."



Malaria & Neglected Tropical Diseases