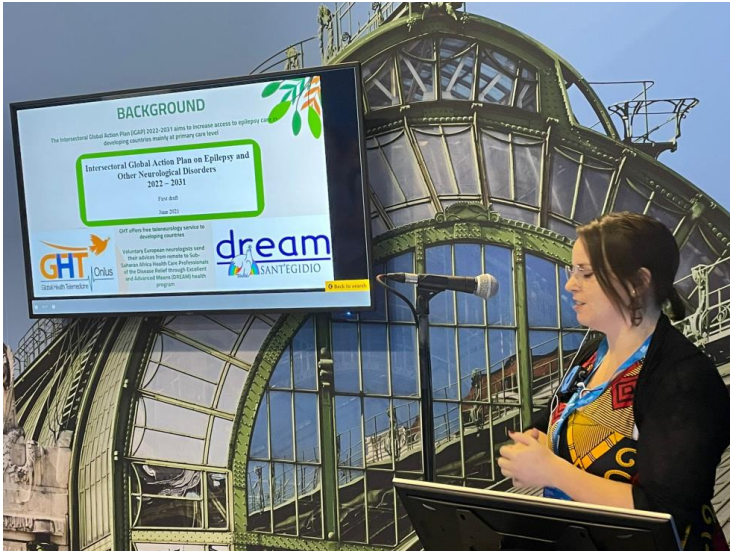




I risultati del Gruppo di Studio “La SIN e i paesi in via di sviluppo dell’Africa subsahariana” presentati all’European Academy of Neurology (EAN) di Vienna e al Congresso Europeo dell’International League Against Epilepsy (ILAE) di Ginevra.

I risultati delle attività del Gruppo di Studio (GdS) della SIN “La SIN e i paesi in via di sviluppo dell’Africa subsahariana” sono stati presentati ai recenti congressi dell’European Academy of Neurology (EAN) di Vienna (comunicazione orale della Drssa Maria Tappatà, foto) e al congresso europeo dell’International League Against Epilepsy (ILAE) di Ginevra (poster, Drssa Domenica Immacolata Battaglia).



Le presentazioni hanno messo in luce il crescente numero di teleconsulti di neurologia tra Europa ed Africa, frutto del lavoro congiunto tra GdS SIN-Africa e varie istituzioni.

Il GdS SIN opera in partenariato col programma Disease Relief through Excellent and Advanced Means (DREAM) in Africa, la Global Health Telemedicine (GHT) e varie Istituzioni di neurologia. Si tratta di una innovativa interazione tra società scientifiche, istituzioni e società civile in linea con le indicazioni del recente *Intersectoral Global Action Plan on Epilepsy and other neurological disorders* (IGAP) della World Health Organization (WHO).

Uno dei risultati più evidenti, e che forse non ci aspettavamo in tempi così brevi, è stata la veloce crescita del numero dei teleconsulti neurologici, prevalentemente per epilessia richiesti dai colleghi africani: una crescita esponenziale. Grazie alla piattaforma GHT, neurologi e neuropsichiatri infantili offrono su base volontaria la loro expertise ai clinici dei centri africani. Nessuno di questi è neurologo, spesso neppure medico. La grave carenza di medici ha portato ad una organizzazione dei sistemi sanitari africani per cui oltre il 90% dei malati neurologici è gestito da *non physician clinicians*. Sarà così per molte decadi.

L’installazione nel 2021 di due video EEG presso i centri DREAM del Malawi - donato dalla SIN - e della Repubblica Centrafricana è stata accompagnata a percorsi di formazione su epilessia e neurologia di base per il personale locale, formazione condotta sia in presenza che da remoto. Un percorso virtuoso che vede via via migliorare comunicazione e relazione tra clinici africani e neurologi europei.

Epilepsy management in sub-Saharan Africa and teleneurology. Tracking the Intersectoral Global Action Plan 2022-2031

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INTRODUCTION

The Intersectoral Global Action Plan (IGAP) 2022-2031 aims to increase access to epilepsy care in developing countries mainly at primary care level.

Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022 - 2031

GUIDING PRINCIPLES

- Primary healthcare
- Integrated approach
- Access the life course
- Intersectoral action

In Sub-Saharan Africa (SSA)

- 2/3 of people with epilepsy (PWE) have no access to treatments;
- there is 1 neurologist every 2 millions inhabitants²⁴;
- more than 90% of PWE are managed by health care providers (HCP) whose education in neurology is insufficient.

In SSA there are more than 26 millions of HIV+ people and HIV is a risk factor for epilepsy.

IGAP calls to better integrate epilepsy and HIV.

Teleneurology brings neurologists where there are none: to work properly it requires a certain education in neurology.

OBJECTIVES

We report on the impact of education and training to local HCP on teleneurology requests from primary care HIV-centres in SSA.

METHODS

Global Health Telemedicine (GHT) offers free teleneurology service to developing countries. Voluntary European neurologists send their advices from remote to SSA HCP of the **Disease Relief through Excellent and Advanced Means (DREAM)** health program operating in 10 SSA countries.

Teleneurology DREAM-GHT

Since 2002 in 10 nations:

- 10 countries: Mozambique, Malawi, Tanzania, Kenya, Republic of Guinea (Freetown), Congo RDC, Central African Republic, Eswatini, Cameroon and Nigeria
- 50 health centres plus 28 laboratories including molecular biology
- +500.000 HIV+ pts monitored with regular follow up including clinical monitoring, blood samples, education, prevention, communities involvement. All data stored in the Dream software
- HIV, TB, malaria, cervical cancer, breast cancer, hypertension, diabetes, **epilepsy**, stroke prevention, malnutrition, obesity etc
- > 130.000 HIV free children born from HIV+ mothers

All the DREAM personnel is local and is given continuous education on various topics.

In Malawi and Central African Republic (CAR)

DREAM follows 18770 patients: 81% are HIV+, 820 (4.4%) suffer from epilepsy.

	Malawi	CAR	SSA	All
N. of patients	12180	2356	18899	26335
Q	12076	2354	11180	2023
Age (mean)	45.5	51	51	47
N. of HIV+ pts	10128	189	13277	85.6
N. of epileptic pts	520	58	624	4.4
N. of hypertensive pts	896	114	1170	6.7
N. of diabetic pts	77	314	391	2.1
N. of pts with BMI >30	2237	56	1333	7.3

The Italian Society of Neurology, the C.Besta Neurologic Institute and the Mariani Foundation joined the DREAM-GHT epilepsy program in Malawi and CAR.

In 2021 two **video-electroencephalograms** were installed and **6 face-to-face education and training courses** have been delivered to local HCP: 4 in Malawi, 2 in CAR. Several sessions from remote were also offered. In addition to basic knowledge in neurology and epilepsy, integration with HIV was part of the education and training program.

RESULTS

In 2021 teleneurology consultations were 802 compared to 141 in 2020; >90% were for PWE

CONCLUSIONS

- Education and training to SSA HCP improves teleneurology between local HCP and European specialists.
- Developing IGAP in SSA requires enhanced and tailored education programs on epilepsy.
- The HIV-primary-care network offers a reasonable platform to develop IGAP in SSA

References

¹ WHO, <https://www.who.int/news-room/factsheets/detail/epilepsy>, 2022, pp. 1-2

² The Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders, 2022

³ M. Leone et al. "Teleneurology in sub-Saharan Africa: Experience from a long-lasting HIV/AIDS health program (DREAM)", *J Neurol Sci*, 2019 Aug 15; 391: 100-111. doi:10.1016/j.jns.2019.06.015. Epub 2019 Jun 15. <https://www.ncbi.nlm.nih.gov/pubmed/31202999>

Nel recente documento IGAP-WHO gli stati firmatari - quasi 200 - si sono impegnati a garantire l'accesso alle cure primarie per epilessia e altre malattie neurologiche a un miliardo di persone entro il 2031. E' noto come l'epilessia sia largamente diffusa nei Paesi africani, con un pesante impatto sulla vita di milioni di malati. Oltre alla carenza di farmaci e specialisti, i pazienti e le loro famiglie devono affrontare uno stigma atroce causa di isolamento sociale che rende ancora più gravoso il peso della malattia. Una grande sfida che richiede formazione, fornitura di farmaci e tecnologie per portare neurologi dove non ce ne sono, specie nelle primary care dell'Africa subsaariana dove il treatment gap è in assoluto il peggiore a livello globale.

A distanza di poco più di un anno dall'installazione dei due video-elettroencefalografi cresce una rete sanitaria locale in grado di dare accesso a cure di eccellenza a un numero crescente di malati con epilessia (oggi oltre mille). Replichiamo così i risultati ottenuti in Africa dal programma DREAM in 20 anni di cura di un'altra malattia cronica, l'HIV.

Cresce il numero dei malati con epilessia in cura, cresce il numero dei teleconsulti di neurologia; e neurologi di tutta Italia e operatori africani imparano sempre più a lavorare assieme. Pur tra non poche difficoltà, sono risultati significativi di un modello innovativo di neurologia territoriale EuroAfricano: una risposta italiana alle indicazioni dell'IGAP-WHO.

Bologna e Milano, 18 Agosto 2022

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Gruppo di Studio "La SIN e i paesi in via di sviluppo dell'Africa subsahariana"

https://www.neuro.it/web/eventi/NEURO/gruppi.cfm?p=PAESI_SVIL_AFRICA_SUB_SAHARA



The Study Group “The Italian Society of Neurology and developing countries of sub-Saharan Africa” at the European Academy of Neurology (EAN) in Vienna and the European Congress of the International League Against Epilepsy (ILAE) in Geneva.

After two years of pandemic, congresses in attendance could finally begun again, and the Study Group (GdS) "The Italian Society of Neurology (SIN) and the developing countries of sub-Saharan Africa" has not missed the chance.

At the Viennese congress of the European Academy of Neurology (EAN) Dr. MariaTappatà (Figure 1) discussed as oral presentation main results of the common work between the GdS SIN Africa, some neurology institutions, the Global Health Telemedicine (GHT) and the Disease Relief through Excellent and Advanced Means (DREAM) program in Africa. The network involves scientific societies, institutions and civil society to respond to the World Health Organization (WHO) *Intersectoral Global Action Plan on Epilepsy and other neurological disorders* (IGAP). Our results have also been presented as poster at the European congress of the International League Against Epilepsy (ILAE) in Geneva (Dr. Domenica Immacolata Battaglia).

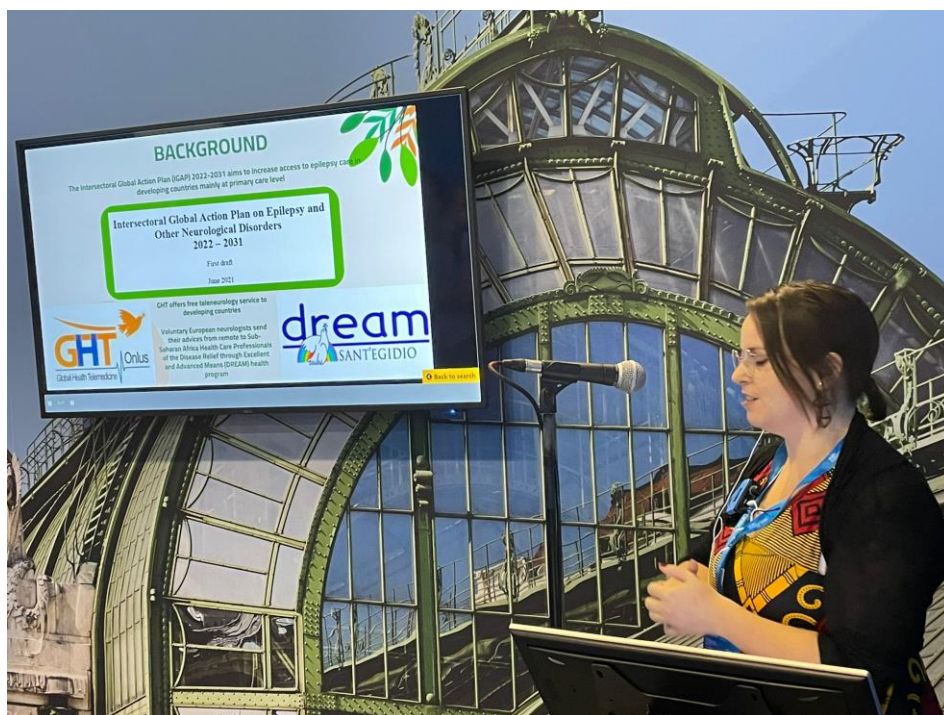


Figure 1

In the recent WHO document almost 200 countries signed the IGAP for epilepsy and other neurological diseases to improve access to diagnosis and treatment to neurological diseases particularly at primary care level in developing countries as sub-Saharan Africa where the treatment gap is the highest. A billion people is the target population before 2031. Education and training of health care providers, drug provision, technologies are needed to bring neurologists where there are none.

Sub-Saharan African countries have the highest number of patients with epilepsy: there, the disease burden has more than doubled in 20 years. In addition to shortage of drugs and specialists, patients and their families have to face an excruciating stigma, leading to social isolation that makes the burden of the disease even more burdensome.

Epilepsy management in sub-Saharan Africa and teleneurology. Tracking the Intersectoral Global Action Plan 2022-2031

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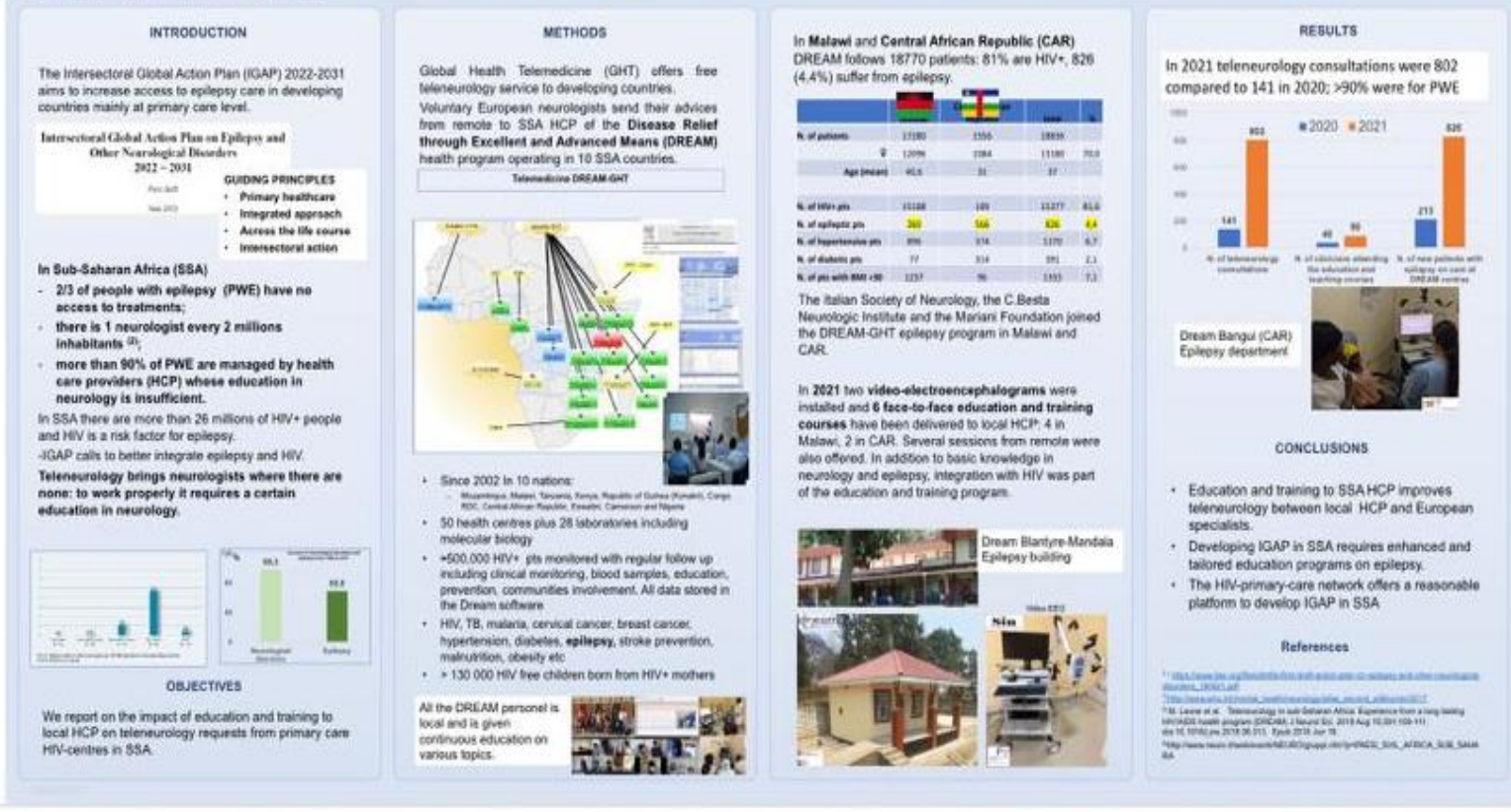


Figure 2

Our results highlight something we even did not expect in the short term, ie the fast increasing number of teleneurology requests - mainly for epilepsy - from African health care providers (Figure 2). Thanks to the GHT platform, neurologists and pediatric neurologists offer advices to African clinicians. Teleneurology requests are mainly from DREAM health centers in Malawi and Central African Republic where video EEG machinaries have recently been installed. GHT also allows to upload and send EEGs to European specialists that in turn offer focused advices. The SIN has generously donated one of the two video EEG machinaries (Malawi).

Education and training on basic neurology and epilepsy offered to African health care personnel (many are not doctors) - both in person and from remote - are playing a key role. Local staff is improving knowledge on epilepsy and general neurology enhancing their skill to do questions to remote specialists: a process increasing communication and relationship between Europe and Africa. African patients will benefit more and more.

In conclusion, just a year after the installation of two video-electroencephalography machines at DREAM centers in Africa, a health network is developing. The good results obtained in the last 20 years at DREAM centres in the treatment of another chronic disease, HIV can be replicated for epilepsy too. As requested by IGAP, the GdS SIN-Africa develops excellence neurology care at primary care level to improve access to more and more patients harboring epilepsy in Africa. Let's start here.

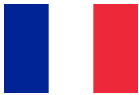
Bologna and Milano, August 18th 2022

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The Study Group "The Italian Society of Neurology and developing countries of sub-Saharan Africa"
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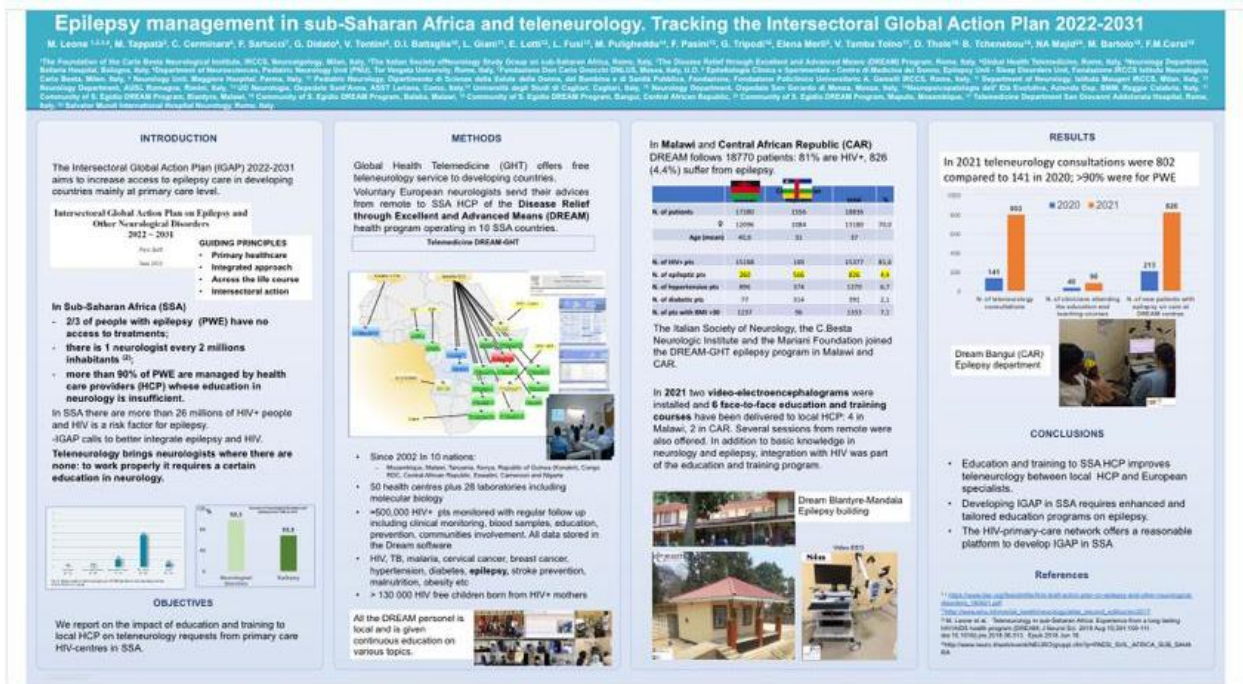
A près deux ans de pandémie, les congrès en présence ont enfin repris, et le Groupe d'Etude (GdE) "Société Italienne de Neurologie (SIN) et les pays en développement d'Afrique subsaharienne" n'a pas manqué sa présence.

Lors du congrès viennois de l'Académie européenne de neurologie, j'ai illustré dans une présentation orale certains des résultats produits par l'action coordonnée du GdE SIN Africa avec diverses institutions de neurologie, Global Health Telemedicine (GHT) et le programme DREAM en Afrique.

Une interaction entre sociétés savantes, institutions et société civile qui répond au grand projet IGAP "Plan d'action mondial intersectoriel sur l'épilepsie et autres maladies neurologiques". Des données similaires ont été apportées sous forme d'affiches au congrès européen de l'ILAE, la Ligue internationale contre l'épilepsie, qui s'est tenue à Genève (Dr Domenica Immacolata Battaglia).

Dans le récent document de l'Organisation mondiale de la santé, les États signataires - près de 200 - s'engagent à investir dans le diagnostic et le traitement des maladies neurologiques dans le but de donner accès aux soins à un milliard de personnes qui n'ont pas accès aux soins primaires et ces sont ceux de l'épilepsie et d'autres maladies neurologiques. Une grande promesse et un pari qui prévoit, entre 2022 et 2031, des formations et des informations, ainsi que des plans d'accès au diagnostic et au traitement dans tout le Monde, en particulier dans les zones rurales et les moins desservies par les services de santé.

On sait que l'épilepsie est très répandue dans les pays africains, limitant extrêmement la vie quotidienne de ceux qui en souffrent. En plus de la pénurie de médicaments et de spécialistes, les patients et leurs familles sont également confrontés à une stigmatisation atroce qui cause l'isolement social, qui rend le fardeau de la maladie encore plus lourd.



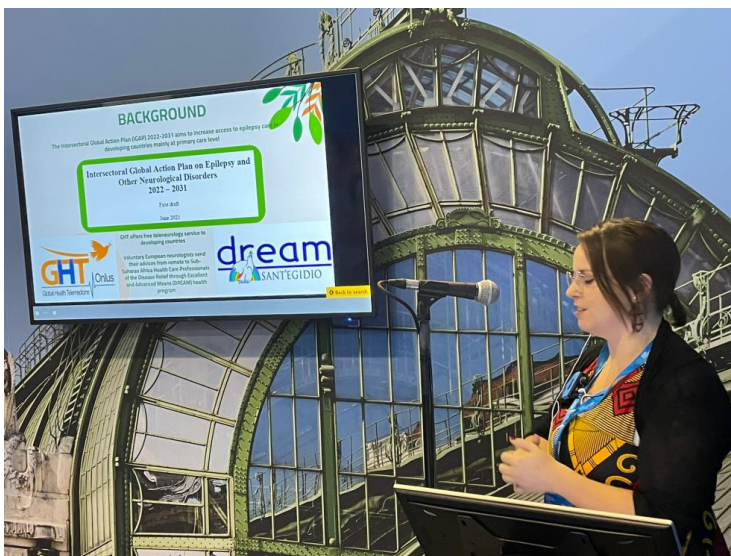
De nombreux spécialistes parmi les auteurs, de toute l'Italie et de l'Afrique: un résultat déjà formidable, une indication du long travail d'implication et de coopération qui découle de GdE Afrique qui depuis plus de 2 ans met en relation des spécialistes passionnés d'Afrique dans le contexte de la SIN.

L'un des résultats les plus sensationnels auquel on ne s'attendait peut-être pas en si peu de temps et dans cette mesure a été la croissance rapide du nombre de téléconsultations neurologiques, principalement pour l'épilepsie demandées par des collègues africains ces dernières années. Une croissance exponentielle. A travers la plateforme GHT, des neurologues et pédopsychiatres apportent bénévolement leur expertise aux cliniciens des centres africains. Les téléconsultations proviennent principalement des centres de santé du Malawi et de la République centrafricaine, où des stations ont été installées pour enregistrer et télécharger l'EEG grâce également au soutien du SIN.

Dans ces mêmes endroits, au cours des deux dernières années, de nombreuses sessions théoriques et pratiques de formation spécifique à l'épilepsie ont été organisées en personne et à distance. Le personnel local a ainsi acquis les connaissances de base pour reconnaître la pathologie, et formuler des questions pertinentes, ciblées et compréhensibles pour nous spécialistes.

En résumé, un peu plus d'un an après l'installation de deux électroencéphalographes dans les centres DREAM en Afrique, on assiste à la consolidation d'un réseau de santé efficace qui reproduit les bénéfices pour la population apportés par le traitement d'une autre maladie chronique, le VIH.

C'est un modèle de gestion qui fête ses 20 ans, et qui aujourd'hui nous facilite aussi nous neurologues en favorisant les cliniciens locaux (beaucoup ne sont pas médecins) dans les bonnes pratiques de soins aux patients. Comme demandé par le Plan d'action mondial intersectoriel, nous répondons à la demande d'accès à la santé pour les patients neurologiques en Afrique. Commençons par ici.



Dr Maria Tappatà at the European Academy of Neurology

Bologna e Milano, 18 Agosto 2022

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