

This is hepatitis... e-Alert



Happy New Year! It's hard to believe that four months from today will be World Hepatitis Day 2010! The global planners have been very busy the last couple of months working on the 2010 campaign. I've included some updates in this email, and you will be receiving more updates in the coming days and weeks. Due to the size of some of the files, we're working on getting a website where you can access the monthly newsletters, graphics and template flyers/posters. Be on the lookout for an email that directs you to this new site.

World Hepatitis Day 2010

Over the last two years, the 'Am I Number 12?' brand has allowed the World Hepatitis Alliance (WHA) to communicate with a broad audience in a simple way to generate mass awareness around hepatitis B and C. In 2010, the brand will be supported with a new two year communication theme '**This is hepatitis...**' which will tell the global human story of viral hepatitis, focusing on the real life impact of these diseases to generate increased understanding and awareness among the general public.

As part of the '**This is hepatitis...**' campaign the WHA will be working with patient groups to develop a documentary that tells a broad range of compelling, personal stories to demonstrate the scale and diversity of the global epidemic and hence its relevance to us all. The WHA hopes this documentary will help normalize and de-stigmatize viral hepatitis so that it becomes acceptable to talk about the diseases. **We are asking for your help in identifying people who would be willing to contribute their stories to the documentary.**

The one hour documentary will feature a number of stories from various countries, and will aim to explain the progression of hepatitis B and C. Using footage of people recalling their personal experience of one of the two diseases, the documentary will chart the positive stories of hope, achievement and success in the face of adversity, but also the impact the viruses can have on daily life for people living with hepatitis B and C. The documentary will be adapted for global distribution either through social media tools such as YouTube, at local patient group screening events or, if the quality of footage is strong enough, in partnership with a global broadcast company. The documentary will form an important part of the WHA's global media campaign around World Hepatitis Day and will focus world attention on a potential resolution to be debated at the 2010 World Health Assembly. When the documentary is distributed it will be accompanied by a global press release announcing the launch of the documentary, as well as materials for adaption as part of local screening and awareness raising events.

We Need You! To bring the one hour documentary successfully to life the WHA is seeking your support in identifying and filming patients for the documentary. We are looking for compelling real life stories of individuals affected by hepatitis B and C. The personal stories that we receive from you will be reviewed and a shortlist of patients will be invited to participate in the documentary.

This is a great opportunity to take part in a global program and, as a participating group, the documentary will be made available to you for promotion and awareness-raising in your own country. The success of this documentary relies on the participation of patient groups and we need your support in sharing compelling patient case studies - without them the documentary will not be possible.

The deadline for submitting your interest in participating in the documentary is **Tuesday, January 26, 2010**. Please see the attached document for more information on the documentary.

World Hepatitis Day Blog

The World Hepatitis Alliance is launching a new global website and blog to promote the ‘**This is hepatitis...**’ campaign ahead of World Hepatitis Day 2010. The new website will feature new and updated content as well as offering users interactive tools, including the ‘**This is hepatitis...**’ blog. Please see the attached document for more information on the blog.

World Cancer Day

In 2010, World Cancer Day on 4th February will focus on raising awareness of cancer-causing infections, of which two of the most prevalent are the hepatitis B virus and hepatitis C virus. Please find attached a joint letter from the President of the World Hepatitis Alliance and the CEO of the International Union Against Cancer about World Cancer Day which contains information to support you in raising awareness of the link between viral hepatitis and cancer and promoting prevention strategies in your country.

World Hepatitis Alliance Membership

The WHA is currently seeking member organizations. This process is in advance of the Alliance’s election process for new board members. If you haven’t already signed your organization up to be a member, I encourage you to do so. There is no membership fee. Please see the attached document for more information on World Hepatitis Alliance membership. Due to the global nature of the WHA, there may be a delay in receiving confirmation of your membership.

Communications about World Hepatitis Day

It has come to our attention that some people have received multiple and identical emails from the World Hepatitis Alliance. We’re working to fix this problem. In the future, you may receive updates from me or directly from the global planners. As always, if you have questions or concerns, please let us know.

Thank you again for your continued dedication to raising awareness about viral hepatitis. I look forward to working with you and hearing about your efforts to make World Hepatitis Day 2010 a success!

Attachments (4)



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National Alliance of State & Territorial AIDS Directors
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ctaylor@NASTAD.org www.NASTAD.org

"Bridging Science, Policy, and Public Health"

Notice: This email message, together with any attachments, contains information of the National Alliance of State and Territorial AIDS Directors (NASTAD) that may be confidential, proprietary, copyrighted and/or legally privileged, and is intended solely for the use of the individual or entity named in this message. If you believe you are not the intended recipient and that you have received this message in error, please immediately return this by email and then delete it. Thank you.

P *Please consider the environment before printing.*

16th December 2009

Dear Colleagues,

Joining Forces to Raise Awareness of Cancer-Causing Viruses

In 2010, World Cancer Day will focus on raising awareness of cancer-causing infections, of which two of the most prevalent are the hepatitis B virus (HBV) and hepatitis C virus (HCV).

Primary liver cancer causes an estimated 598,000 deaths worldwide every year and approximately 80% of liver cancer is caused by the long-term consequences of infection with HBV and HCV. Vitaly, these diseases are preventable through safe healthcare and behavioural change that directly reduces exposure to specific risk factors. In the case of hepatitis B there is an effective vaccine available.

In recognition of the scale of the problem, the World Hepatitis Alliance (WHA) and the International Union Against Cancer (UICC) are joining forces to mark World Cancer Day on 4th February. At a global level, we are working together on the preparation of materials and coordinated media activity. However, we hope that both organisations' members will also cooperate to raise awareness of the link between viral hepatitis and cancer and promote prevention strategies in their own countries. This might include arranging a joint event, hosting a press conference or publishing a disease information leaflet.

We have established a Patient Group Liaison Lead to put members of both the WHA and UICC in touch with their national counterparts. Italo Goyzueta can be reached by email, Goyzueta@uicc.org, or telephone: +41 22 809 18 27. More information on UICC and WHA members can also be found on the [WHA website](#) and [UICC website](#).

World Cancer Day 2010 provides an excellent opportunity for cooperation toward our shared objectives, and the potential benefits are great. Working together our voice is louder, we are more persuasive and we can reach new audiences. We encourage you to take advantage of this unique opportunity in 2010 and look forward to hearing about the results.

With best wishes.

Yours sincerely,



Charles Gore
President
World Hepatitis Alliance



Cary Adams
Chief Executive Officer
International Union Against Cancer

World Hepatitis Alliance Calls for Bloggers to Join the New World Hepatitis Day Blog



This is **Andrew...**

Andrew, who is a haemophiliac, contracted hepatitis C in the late 1980s as a result of a blood transfusion. For many years, Andrew was so sick that he had to end his career. [Read Andrew's Story](#)

This is **hepatitis...**

LATEST BLOG POSTS

LATEST COMMUNITY POSTS

[Read all Blog posts](#)

Introduction

The World Hepatitis Alliance is launching a new global website and blog to promote the **'This is hepatitis...'** campaign ahead of World Hepatitis Day 2010. The new website will feature new and updated content as well as offering users interactive tools, including the **'This is hepatitis...'** blog.

The **'This is hepatitis...'** blog aims to provide a forum in which people around the world can come together and talk about their experiences of viral hepatitis.

Interested in taking part?

As part of the new blog we will be providing 12 people from 12 different countries a unique opportunity to tell their personal story through the launch of their own blog and you can be one of them!

This is a great opportunity for someone with a personal experience of viral hepatitis to help educate people on what it means to live with hepatitis B and C, and to help change the way people think about the diseases. For those taking part we hope that it will be a positive experience and through educating visitors to the site, the participants will help increase awareness, improve understanding and empower patients to speak out about their own experiences and to play a vital role in educating and supporting others.

Participants will have a dedicated personal blog through which they can regularly post stories and information in their own language about relevant and topical issues in the field of viral hepatitis. If

you are interested in taking part as one of the 12 bloggers, then please complete the application form on the following page. As an example, blog post topics could include:

- Personal experiences of living with or battling viral hepatitis
- Day-to-day insights of how viral hepatitis can affect a person's life
- Comments and thoughts on regional hepatitis B and C stories in the news
- Events in your local area and your involvement in patient advocacy work

Blogger Application Form

Thank you for your interest in taking part in the new '[This is hepatitis...](#)' blog, being launched by the World Hepatitis Alliance. As there are only 12 positions available on the new blog please complete the following as fully as possible in English.

Name:

Country:

Telephone:

Mobile / Cell:

Email address:

Will you be able to dedicate a proportion of your time each week to your blog i.e. ensuring regular posts feature on your blog? (each post should be around 100 to 200 words in length):

Yes

No

Maybe

In approximately 100 words can you please provide a short biography/summary of who you are:

In approximately 100 words can you please provide a summary of why you would like to become a blogger on the new World Hepatitis Day blog:

Please return your application form to contact@worldhepatitisalliance.org. We will be reviewing all completed application forms during January with a view to making a final selection at the end of the month. Thank you for your expression of interest.



7, Rue du Marché
1204 Geneva
Switzerland

Documentary: The Hidden Truth of a Global Epidemic Request for Patient Case Studies

Background

Over the last two years, the 'Am I Number 12?' brand has allowed the World Hepatitis Alliance (WHA) to communicate with a broad audience in a simple way to generate mass awareness around hepatitis B and C. In 2010, the brand will be supported with a new two year communication theme '**This is hepatitis...**' which will tell the global human story of viral hepatitis, focusing on the real life impact of these diseases to generate increased understanding and awareness among the general public.

As part of the '**This is hepatitis...**' campaign the WHA will be working with patient groups to develop a **documentary** that tells a broad range of compelling, personal stories to demonstrate the scale and diversity of the global epidemic and hence its relevance to us all. The WHA hopes this documentary will help normalise and destigmatise viral hepatitis so that it becomes acceptable to talk about the diseases.

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The Documentary

The one hour documentary will feature a number of stories from various countries, and will aim to explain the progression of hepatitis B and C. Using footage of people recalling their personal experience of one of the two diseases, the documentary will chart the positive stories of hope, achievement and success in the face of adversity, but also the impact the viruses can have on daily life for people living with hepatitis B and C.

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Step 1: Getting Consent

Hepatitis B and C continue to be stigmatised diseases and it can be a big step for a person to discuss their story in the media or in public. It is important to ensure the person you recommend is aware that you are suggesting them as a case study and they understand their potential role in the documentary.

Please note: At this stage all of their information will be strictly confidential and the WHA will not share any of their details with any third parties. If the person is chosen to be included in the documentary the WHA will ask the individual to sign a consent form, which will provide further details about their involvement in the campaign.

Step 2: Prepare your Case Study Submission

Each person you suggest will require a separate submission form (pages are included at the end of this document for your completion – please add more pages if required). The WHA is looking for personal accounts of the impact that hepatitis B and C can have on people’s lives and the most compelling stories will be chosen for inclusion in the documentary.

As a guide to helping you identify suitable case studies we have included five example profiles of the different types of stories that you might want to submit – covering people’s experiences of being newly diagnosed, battling stigma, making decisions about treatment, confronting the need for a liver transplant and coping with the unfortunate reality for some - death. Please note that these are only examples, and you will no doubt have many different compelling stories that you want to propose:



Profile 1: Newly Diagnosed

The battle of confronting a diagnosis is often so frightening that people do not get tested, just to avoid being given the bad news. Although upsetting, finding out you have viral hepatitis is not a death sentence and it is better to confront the disease head on, know how to avoid transmitting the infection to others and consider your treatment options as early as possible. Fear of the stigma is another deterrent to getting tested.



Profile 2: Battling Stigma

For many people living with viral hepatitis one of the biggest hurdles they will face is combating the stigma that accompanies the diseases. Stigma can take many forms and can include being shunned and discriminated against, losing a job or even being rejected from a community. For some, this means living a life of shame and fear. Living with viral hepatitis can change your life forever and seeking out the right support system can make life easier.

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Profile 3: Treatment Decisions and Results

For the majority of those with chronic viral hepatitis treatment is not an option because they cannot access it. For those who can, the decision to start treatment is a significant one and in some cases can be difficult to make. There are many factors that will inform whether you should start treatment and an open and honest dialogue with your doctor will help you make the right choice. Once you do begin treatment it is important to have a strong support network around you and to prepare for the side effects that accompany many treatments. Successful treatment can revolutionise people's lives and the inspiring stories of effective treatment can motivate others to either initiate or continue with their treatment regimen.



Profile 4: End Stage Disease

For some people a diagnosis comes too late for conventional treatment and the only option is a liver transplant. End stage liver disease can be a harrowing experience, but despite the complexity and risks associated with transplantation, it has a good success rate and people should not give up hope if they are faced with the reality of a liver transplant.



Profile 5: Death

For the majority of people with end stage liver disease, especially primary liver cancer, transplantation is not an option. In the developing world advanced viral hepatitis is often a death sentence with all the accompanying emotional and financial implications for the individual and their family.

Step 3: Submit your Case Study Submission

Please ensure you complete the submission form as fully as possible, providing as much information as possible – and don't forget to include a photo of the person you are suggesting.

The submission form should be completed and returned to contact@worldhepatitisalliance.org by **Tuesday 26th January, 2010**. Submissions should also be completed in English wherever possible. The WHA will contact you at the beginning of February to confirm whether your case study has been chosen for inclusion in the documentary.

Please note: Filming for the documentary is due to take place in February and March 2010. Therefore it is important that the recommended candidates be available for filming at this time. If you have any questions about the documentary and the information requested please email contact@worldhepatitisalliance.org



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Documentary Case Study Submission

Your Name and Contact Details:
Name of Candidate:
Case Study Introduction (age, occupation (if any) or past career, family details – any children):
What is their connection with hepatitis B or C?
If they are living with hepatitis B or C, how long ago were they diagnosed?

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How long do they think they were living with hepatitis before they were diagnosed?

How did they discover they had the disease?

Has their experience of hepatitis had an impact on their career or led to any negative implications?

What emotional impact has hepatitis had on their life?

How have they coped with their experience of hepatitis?

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Is there anything else from their story that would motivate or inspire people living with hepatitis?

World Hepatitis Alliance Membership Application Pack

Introduction

This information pack explains what the World Hepatitis Alliance is, what its aims are and how to join. It has the following sections:

- The World Hepatitis Alliance, Mission and Activities (p.1)
- The World Hepatitis Alliance Structure (p.2)
- Membership Categories, Benefits and Obligations (p.2)
- How to apply for Membership (p.4)
- Membership Application Form (p.5)
- List of countries by region (p.7)

Membership is currently free but is limited to organisations; it is not open to individuals.

The World Hepatitis Alliance, Mission and Activities

The World Hepatitis Alliance (WHA) is a not-for-profit international umbrella Non-Governmental Organisation (NGO) established in December 2007 in Geneva, Switzerland, whose membership is composed of organisations working in the field of viral hepatitis. It is patient-led and patient-driven. It is not aligned with any party political views, does not engage in political activity and does not discriminate on the basis of creed, religion, lack of religion, ethnicity, sex or sexual orientation.

World Hepatitis Alliance Mission Statement

The WHA provides global leadership and supports action that will halt the death toll and improve the lives of people living with chronic viral hepatitis B and C. Through better awareness, prevention, care, support and access to treatment, our ultimate goal is to work with governments to eradicate these diseases from the planet.

World Hepatitis Alliance Vision Statement

World Hepatitis Alliance – Seeking a world without viral hepatitis B & C.

The activities of the WHA include, but are not limited to:

- Raising awareness of chronic viral hepatitis. In particular this involves coordinating global activities for World Hepatitis Day which occurs every year on 19 May and supporting regional and national World Hepatitis Day programmes
- Reducing the stigma associated with chronic viral hepatitis by improving education and understanding of chronic viral hepatitis
- Working with the World Health Organization to give viral hepatitis the profile and priority it must have
- Working with member groups to help them ensure that every country has an effective strategy in place to combat viral hepatitis
- Supporting member groups and helping them to build capacity
- Liaising with other NGOs to secure support and endorsement for the work of the WHA, its member groups and the annual World Hepatitis Day

Structure

The World Hepatitis Alliance (WHA) is composed of Members which are organisations with a primary interest in chronic viral hepatitis. Individuals may not be Members but umbrella organisations may be.

The WHA is governed by an Executive Board, consisting of a President and 8 Regional Board Members each representing one of the following world regions:

- North America
- Latin America
- Europe
- Africa
- Eastern Mediterranean
- SE Asia
- Western Pacific
- Australasia

The 8 Regional Board Members, each of whom must be a senior officer of a Full Member whose principle registered office is within the region he/she is representing, are elected by a majority vote of the Full Members of their respective regions.

In line with the philosophy of the WHA, the role of the Regional Board Members is:

- to support, advise and liaise with patient groups in their region
- to represent those patient groups and their interests within the WHA
- where requested, to help patient groups with national advocacy
- to encourage patient groups to work together, both nationally and regionally, to give the Alliance greater cohesion and strength
- to engage with their WHO Regional Office
- to build capacity within the region
- to act as a spokesperson on behalf of the Alliance as a whole

The role of the Regional Board Members is not to dictate to patient groups in their region what they should do or how they should operate.

The President represents the whole membership and is elected by majority vote of the Regional Board Members.

Membership Categories, Benefits and Obligations

There are two types of membership – full membership and associate membership. There are currently no fees for membership.

All members will be able to use membership logos and will have access to template campaign material, including awareness-raising, advocacy and fundraising tools, as well as support and advice from the World Hepatitis Alliance (WHA).

In line with the principle aims of the WHA, all members are expected to take part in awareness-raising activities around World Hepatitis Day each year, to work together, in as far as is possible, with other members operating in their country, to present their respective Governments with policy requests and to communicate their activities to the Executive Board at least annually.

Members are also expected to interact with other patient groups both within their region and worldwide to help share best practice and support common national, regional and global goals.

Only Full Members have voting rights entitling them to vote at annual meetings and therefore to elect the Regional Board Member for their geographic region.

Full Membership

The WHA is a patient organisation. Consequently all of its full members should ideally be patient-driven, meaning that the needs and views of patients drive each organisation's strategy, policies and activities in a significant way and that the organisation is capable of representing the needs and views of these patients. The WHA accepts that cultural differences may make this difficult in some parts of the world and will therefore permit some flexibility. To become a Full Member, an organisation should fulfil the five criteria below:

- The organisation must be non-profit and non-governmental and must be independent from commercial, political and religious organisations. It can receive sponsorship from commercial companies, if such funding is provided by at least two independent companies and a written agreement is in place.
- The organisation must have a legal status appropriate to its country of origin, with a written constitution and/or by-laws. If no appropriate legal status exists in the country of origin this criteria may be waived at the discretion of the WHA Executive Board.
- The organisation must have chronic viral hepatitis as its primary area of activity.
- The organisation must demonstrate its commitment to patients and the principle of patient-centred healthcare in their guiding statements, such as their vision, mission or organisational objectives, and their activities
- The organisation must have at least one patient on its governing board. Ideally, as stated above, it should be patient-driven, defined in one of the following three ways:
 - (i) The majority of the organisation's voting members are patients¹ or patient representatives².
 - (ii) The majority of the organisation's governing body are patients or patient representatives.
 - (iii) The organisation can demonstrate that it has some other governance structure which ensures that it is patient-driven.

Where an organisation currently has at least one patient on its governing board but is not patient-driven as defined above, the WHA expects it to move towards becoming patient-driven

Associate Membership

A healthcare-related organisation which is not eligible to become a Full Member may become an Associate Member if it meets the four criteria below:

- The organisation must be non-profit and non-governmental.

¹ A 'patient' is defined by the WHA for the purposes of its membership criteria as someone who has or has had chronic viral hepatitis

² A 'patient representative' is defined by the WHA for the purposes of its membership criteria as a person that is significant for a patient or their care, who can represent that patient, for example a partner, parent, family member or close friend. A patient representative should not be a health professional unless they are also a significant relation or friend of the patient they are representing

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- The organisation must have a legal status appropriate to its country of origin, with a written constitution and/or by-laws. If no appropriate legal status exists in the country of origin, these criteria may be waived at the discretion of the WHA Executive Board.
 - The organisation must have a clear interest in chronic viral hepatitis.
 - The organisation must demonstrate commitment to improving healthcare and to the principle of patient-centred healthcare in their guiding statements, such as their vision, mission or organisational objectives and their activities.

How to apply for Membership

Applications for membership should be made to the World Hepatitis Alliance (WHA) Executive Board by emailing the membership application form to membership@worldhepatitisalliance.org. If you wish to submit the application form in some other way, please contact Raquel José by telephone +447920202120 or by post at 27 Crosby Row, London SE1 3YD, UK for guidance.

The application form is available in the 7 languages the WHA uses – Arabic, Chinese, English, French, Portuguese, Russian and Spanish and should be completed in one of those languages. However, translation is a major cost for the WHA so we would prefer applications to be submitted in English if that is possible. We would also prefer to communicate in English but we do not wish language problems to prevent effective communication so the application forms ask which of the 7 languages you can communicate in. While we recognize that this only represents a fraction of the world's languages, it is not logistically possible at the moment to use more.

Election of new members is by majority decision of the Board. Any organisation refused membership will be informed of the reasons in writing. Membership is indefinite but may be ended at any time by a member. It may also be ended by the WHA Executive Board under certain circumstances laid down in the Internal Regulations.

Membership Application Form

MEMBERSHIP APPLICATION

Name of Organisation:

Address:

Website:

Telephone:

Fax:

Legal status (e.g. company):

Registration/incorporation number:

Contact person:

Mobile:

Email address:

Type of membership applied for: Full Membership Associate Membership

If applying for Full Membership, please state:

Number of patients or patient representatives on governing board: _____

Total size of governing board: _____

Number of voting members who are patients or patient representatives: _____

Total number of voting members: _____

Do you have someone in your organisation who is able to communicate in English?

Yes No

If no, please state which other language you wish to use:

Arabic

Chinese

French

Portuguese

Russian

Spanish

Please attach in electronic form **for all applications**:

- Guiding statements, such as their vision, mission or organisational objectives and their activities
- Most recent financial accounts

For **Full Membership** applications only:

- Governing Document (meaning the document that states what the organisation may and may not do)

List of countries by region

North America

- [Antigua and Barbuda](#)
- [Bahamas](#)
- [Barbados](#)
- [Canada](#)
- [Grenada](#)
- [Jamaica](#)
- [Saint Kitts and Nevis](#)
- [Saint Lucia](#)
- [Saint Vincent and the Grenadines](#)
- [Trinidad and Tobago](#)
- [United States of America](#)

Latin America

- [Argentina](#)
- [Belize](#)
- [Bolivia](#)
- [Brazil](#)
- [Chile](#)
- [Colombia](#)
- [Costa Rica](#)
- [Cuba](#)
- [Dominica](#)
- [Dominican Republic](#)
- [Ecuador](#)
- [El Salvador](#)
- [Guatemala](#)
- [Guyana](#)
- [Haiti](#)
- [Honduras](#)
- [Mexico](#)
- [Nicaragua](#)
- [Panama](#)
- [Paraguay](#)
- [Peru](#)
- [Suriname](#)
- [Uruguay](#)
- [Venezuela \(Bolivarian Republic of\)](#)

Europe

- [Albania](#)
- [Andorra](#)
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- [Switzerland](#)
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- [The former Yugoslav Republic of Macedonia](#)
- [Turkey](#)
- [Turkmenistan](#)
- [Ukraine](#)
- [United Kingdom](#)
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Eastern Mediterranean

- [Algeria](#)
- [Bahrain](#)
- [Djibouti](#)
- [Egypt](#)
- [Iran \(Islamic Republic of\)](#)
- [Iraq](#)
- [Jordan](#)
- [Kuwait](#)
- [Lebanon](#)
- [Libyan Arab Jamahiriya](#)
- [Morocco](#)

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Africa

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- [Lesotho](#)
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- [Mali](#)
- [Mauritania](#)
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- [Timor-Leste](#)

Western Pacific

- [Brunei Darussalam](#)
- [Cambodia](#)
- [China](#)
- [Democratic People's Republic of Korea](#)
- [Japan](#)
- [Lao People's Democratic Republic](#)
- [Malaysia](#)
- [Mongolia](#)
- [Philippines](#)
- [Republic of Korea](#)
- [Singapore](#)
- [Viet Nam](#)

Australasia

- [Australia](#)
- [Cook Islands](#)
- [Fiji](#)
- [Kiribati](#)
- [Marshall Islands](#)
- [Micronesia \(Federated States of\)](#)
- [Nauru](#)
- [New Zealand](#)
- [Niue](#)
- [Palau](#)
- [Papua New Guinea](#)
- [Samoa](#)
- [Solomon Islands](#)
- [Tonga](#)
- [Tuvalu](#)
- [Vanuatu](#)