



Using Our PH Library with patients, their families and carers

GUIDANCE DOCUMENT FOR PH PATIENT GROUPS

September 2015

INTRODUCTION

Our PH Library is a website developed jointly by PHA Europe and the US Pulmonary Hypertension Association (PHA US). It provides information and a library of high quality resources on pulmonary arterial hypertension (PAH) for anyone who has been diagnosed with the condition, as well as their families and carers.

www.ourphlibrary.com



In order to be a truly useful resource, it is important that as many PAH patients, families and carers as possible around the world are made aware of Our PH Library. PH patient organizations are ideally placed to assist with this and can play a key role by encouraging their members to access Our PH Library when appropriate to obtain the information they need.

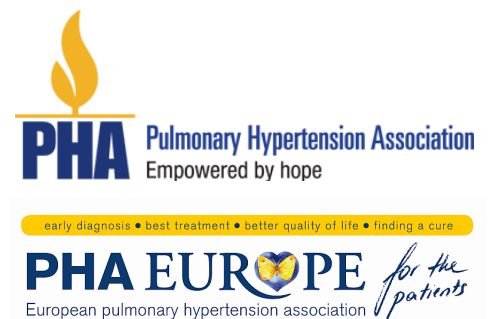
This guidance document has been designed to assist PH patient organizations that wish to use Our PH Library with their members. The document contains:

- An overview of what our PH Library can offer PAH patients, their families and carers
- Advice on ways in which you can use Our PH Library as a patient group
- Suggestions of ways in which PH patient organizations can encourage uptake and usage of Our PH Library by its members

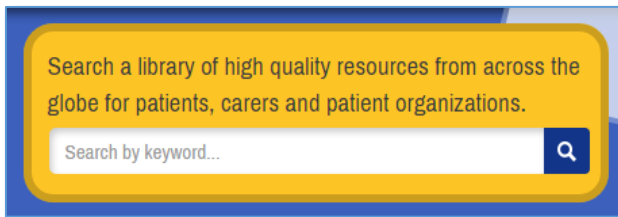
Our PH Library has been developed with the support of an educational grant provided by Actelion Pharmaceuticals Ltd.


OVERVIEW: WHAT OUR PH LIBRARY OFFERS YOUR MEMBERS

- ✓ Brings together high quality resources on PAH from across the globe in a user-friendly format, so patients, families and carers can easily access the information they need
- ✓ Developed by leading patient associations, PHA Europe and PHA US
- ✓ Comprises three modules on PAH, so the user can obtain relevant information at a pace that's right for them
 - Module 1: About PH and PAH
 - Module 2: Research and treatments
 - Module 3: Support



- ✓ Contains an index of more than 200 resources in English and many other languages, easily searchable by topic, keyword, audience or language – translations can be requested if they are not already available, putting you in touch with the originating patient association





Search the index

Topic
- All -

Audience
- All -

Type of resource
- All -

Language filter
- All -

Search by keyword
Search by keyword

SEARCH 🔍

Your search has returned 2 resources:

Title	pediatric Resources for Families
ts, Carers	
ts of information for families of newly diagnosed pediatric patients	
JS	
sh)	
	TRANSLATION REQUEST
ndbook for families	
	TRANSLATION REQUEST
ts, Carers	
information pack for young family members, available upon request by parents for their	
en in the US only, which provides child-friendly advice and related games on PH and how	
er family members can get involved in raising awareness of the condition	
JS	
sh, Spanish)	
	TRANSLATION REQUEST

Search the index

Topic

- All -
- All -
- What is PAH: Symptoms
- Associated diseases
- Children and PH
- Emergency ID
- Emotional and social impact of PH
- Exercise and relaxation**
- Finance
- Guidelines
- Lung transplantation
- Newly diagnosed
- Oxygen therapy
- Patient stories
- Research
- Travel
- Treatment and medication
- Useful materials for patient associations
- Wellbeing

- ✓ Includes a handy directory of more than 70 PH patient organizations in countries around the world.

ARGENTINA



HIPUA (Hipertensión Pulmonar Argentina)
www.hipertensionpulmonarargentina.org

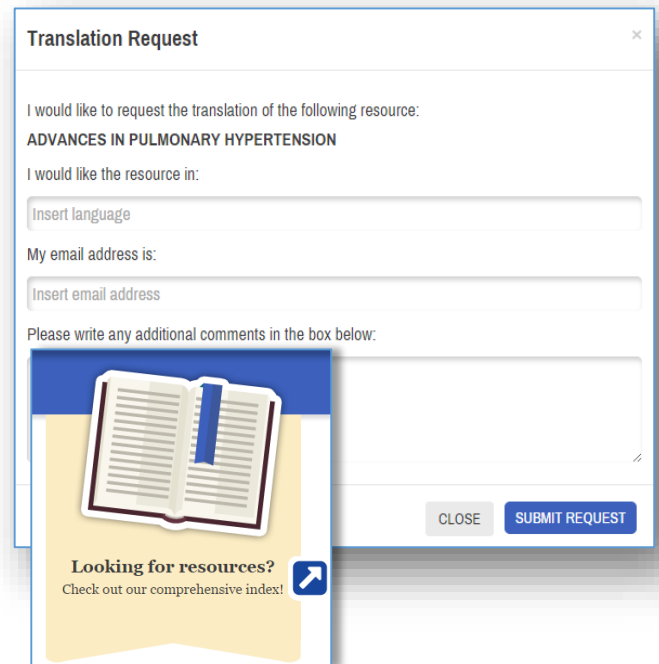
Patient Organizations

List of Organizations by Country/Region - A-Z

↓ A

WHAT BENEFITS DOES OUR PH LIBRARY OFFER PATIENT GROUPS?

- ✓ User-tested and developed with patient group feedback
- ✓ Index linking directly to patient group resources, increasing traffic to your website and awareness of your materials
- ✓ For patients and carers searching for their local patient group, the website directory offers another way for them to find and contact you
- ✓ Easy search function enables you to find resources that other patient groups have developed to share ideas and materials
- ✓ Request translation button puts you in contact with the originating patient group to discuss next steps for translating materials
- ✓ Easy contact page form to allow you to suggest new resources to be added to the library



ENCOURAGING YOUR MEMBERS TO USE OUR PH LIBRARY

Patient organizations can help encourage uptake and usage of Our PH Library among their members in a variety of ways, for example:

1. *Via your newsletters to registered members*

Include information about Our PH Library in your regular newsletter or email update to your registered members.

A paragraph about Our PH Library with the relevant link has been developed for this purpose and can be found in Appendix 1. This paragraph can be adapted as needed and cut and pasted into your newsletter or email update template.

2. *Via your website*

Include information about Our PH Library on your website.

A paragraph about Our PH Library with the relevant link has been developed for this purpose and can be found in Appendix 1, along with an art-worked banner to add visual interest.

3. *Via your social media channels*

Help drive traffic to Our PH Library by tweeting or posting about the resource on your social media channels.

You may like to adapt the paragraph in Appendix 1 for this purpose.

A selection of tweets and tweet cards can be found in Appendix 2.

You could also consider temporarily changing the profile image of your group on Facebook or Twitter and using the banner image provided in Appendix 1.

4. *With journalists as part of your media outreach*

As and when your group is in contact with journalists in your country, you may wish to include information about Our PH Library in your media materials. You can adapt the paragraph in Appendix 1 for this purpose.

5. *By sharing the PH Library card at meetings and congresses*

The PH Library card features the URL for Our PH Library and can be shared at local meetings and congresses. The PH Library card can be found in Appendix 3.

If you would like to order printed copies of the PH Library card, please contact the communications agency supporting us, Packer Forbes Communications: Lisa Seukeran (lisa.seukeran@packerforbes.com) or Jessica Pacey (jessica.pacey@packerforbes.com).

6. *By ensuring group representatives are briefed about Our PH Library*

Ensure that any representatives of your group who interact with members, especially those who may answer a helpline, are aware of the PH Library and can encourage members to use it where appropriate.

APPENDICES

Appendix 1

The following paragraph can be adapted as needed and cut and pasted into communications with your group members, for example as part of newsletters, email updates and social media posts. It can also be adapted for upload to your website and included on any media materials that you share with local journalists.

Our PH Library is a website developed jointly by the European and US pulmonary hypertension associations (PHA Europe and PHA US). It provides information and a library of high quality resources on pulmonary arterial hypertension (PAH) for anyone who has been diagnosed with the condition, as well as their families and carers. Indexing more than 200 resources in English and many other languages and easily searchable by topic or keyword, Our PH Library is an ideal tool for those looking for information on PAH in a user-friendly format.

www.ourphlibrary.com

Screen 1



Screen 2



Appendix 2

The following tweets and tweet-cards can be adapted as needed and shared via your group Twitter handle.

Tweet	Characters
We're excited about the launch of a new library of resources @EuropePHA @PHAssociation on #pulmonaryhypertension www.ourphlibrary.com	140
Looking for information and resources on #pulmonaryhypertension? Look no further... www.ourphlibrary.com	102
Our PH Library indexes over 200 resources on #pulmonaryhypertension in English and many other languages www.ourphlibrary.com	124

Appendix 3

The following PH Library card features the URL for Our PH Library and can be shared at local meetings and congresses.

If you would like to order printed copies of the PH Library card, please contact the communications agency supporting us, Packer Forbes Communications: Lisa Seukeran (lisa.seukeran@packerforbes.com) or Jessica Pacey (jessica.pacey@packerforbes.com).

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FURTHER INFORMATION

If you would like additional information about Our PH Library, or if you need further support in raising awareness about the resource with your members, please contact:

PHA Europe: p.ferrari@phaeurope.org

PHA: info@PHAssociation.org