

ALPHA-1 ADVOCACY CHECKLIST

5 steps to boost Alpha-1 awareness in your country



Step 1

Identify your top political asks & long-term strategy

Step 2

Map the policy-makers

Step 3

Connect with your policy-makers

Step 4

Go live!

Step 5

Celebrate European Alpha-1 Awareness Day

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Identify your top political asks & long-term strategy

⇒ Understand the environment

Do you have treatment in your country? Is it reimbursed? If yes, what else should be improved in relation to *Alpha-1* diagnosis, treatment and care? If not, what can your group do in the patient advocacy arena to contribute to the reimbursement discussion?

What would be your top ask for 2018 from your political representatives? What change you would like to see long-term? In 2-3 years' time?

Check out [European *Alpha-1* Recommendations](#) p. 10-11 for some inspiration!

⇒ Formulate your ask

Use [Alpha-1 Global Guide](#)¹ to develop advocacy messages

Example of political ask

Smoking cessation guidance, optimal pharmacotherapy of respiratory symptoms as well the early detection, and effective treatment of exacerbations are absolutely essential to improve Alpha-1 diagnosis, management and patient outcomes in country X.

Key issues in my country

2018 asks

Strategic goal

¹ Click on "Policy" card, then Click on "Get Started"

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Map the policy-makers

⇒ **Identify active politicians in health at the national level**

Find out who is responsible for rare disease policies (Parliament, Ministry of Health, Medicines Agency etc). If you find there is no dedicated department/committee in your country, map politicians active on general public health policies. You are from Bulgaria, Austria, or Romania? These countries have the forthcoming EU Council Presidencies - urge your government to put *Alpha-1* and rare diseases on the agenda.

⇒ **Find out who represents your interests at the European Parliament!**

National changes can also be triggered by the EU level policy makers!

National representatives

Members of the European Parliament

Other

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Connect with your policy-makers

⇒ Connect with your identified policy-makers on Social Media (Twitter, Facebook, LinkedIn)

Post your developed political asks, recommendations and photos on social media and don't forget to tag them!

National representatives

Find out when and how you can meet you MP/MEP. All Members of the European Parliament have national offices; so, you don't need to come to Brussels to meet them)

Book the meeting (don't take no as an answer)

Do your research. Find out what issues your MP/MEP cares about and whether he or she has an active interest in health policies

Know what you want to discuss: take with you the recommendations and key messages to explain why this is important

Practice speaking: develop a brief for 2-3 minutes to quickly and powerfully introduce your issue to your policy maker

During the meeting

Share your story: facts and figures are important but telling your personal story and showing your commitment is a powerful way to make yourself heard

Be concise: present your case in laconic but engaging way, including an explanation of the issues you are experiencing and your political asks

Make clear and specific requests: having concrete asks to your policy-maker is the best way to encourage a political reply to your issue. Also let your policy maker know about *Alpha-1 Awareness Day*, ask them to support it.

After the meeting

Send a thank you email along with a short summary of your key asks and materials

Follow up: keep your policy-maker posted on the developments and have a follow-up meeting to maintain a relationship

Share your success: post an article about the meeting on your website or newsletter, have a social media post thanking your policy-maker for support

Click [here](#) for more materials!²

² Click on "Policy" card, then Click on "Get Started"

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Go live!

⇒ Post recommendations on your website

⇒ Do you or your organisation have a Facebook or Twitter account?

Then you can:

- spread your message!
- disseminate the *Alpha-1* European Recommendations
- share messages provided by *Alpha-1* Global ahead of European *Alpha-1* Awareness Day
- share MEPs video messages developed ahead of EU *Alpha-1* Awareness Day

⇒ Follow *Alpha-1* Global on Twitter: [@Alpha1_Global](#), [@Alpha1_EEvent](#)

⇒ Retweet tweets [@Alpha1_Global](#) to help us spread the word.

⇒ If you don't have a Facebook or Twitter account, consider creating one

⇒ Tell your story on [Alpha-1 Global Blog](#)

Social media plan

February

March

April

Use tips from [Alpha-1 Global Guide on Social Media](#)³

³ Click on "Policy" card, then Click on "Get Started"

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Celebrate European Alpha-1 Awareness Day

⇒ Celebrate online

- Share *Alpha-1* Global messages
- Use a banner developed for your country
- Share a developed video message from your MEP
- Write an article to a local newspaper/news portal about *Alpha-1* Awareness Day.

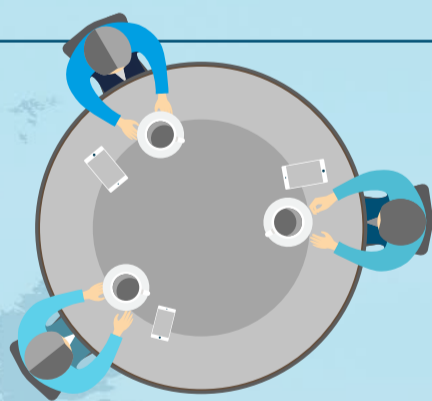
⇒ Have a community event in April 2018



***Organise an event
at your Parliament***



***Host a lecture/workshop on
Alpha-1 together with other
patient advocates and/or
healthcare professionals***



***Organise Alpha-1 community lunch
with policy-makers***



***Disseminate Alpha-1
recommendations in your
healthcare setting***