



ALPHA-1 PATIENT ADVOCACY WEBINAR 2019

31 October 2019



BRUSSELS · BERLIN · LONDON · PARIS · HAMBURG · ROME · VIENNA · CANBERRA · MADRID

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I. INTRODUCTION

On 31 October 2019, [Alpha-1 Global](#), in collaboration with RPP Group, organised an Advocacy Webinar dedicated to the Alpha-1 patient community. The slides of the webinar are [now available](#) on the Alpha-1 Global website as part of their [Advocacy](#) section. The webinar focused on providing Alpha-1 patients with tools and advices to successfully reach out to policymakers to turn their objectives into concrete political messages and actions. Patient representatives had the opportunity to participate in this educational initiative and familiarise themselves with the concrete steps which should be considered when interacting with political stakeholders. During the Webinar, RPP Group presented the Alpha-1 Advocacy Checklist – a guide developed by the Alpha-1 Foundation, in cooperation with RPP Group. The checklist is [now available](#) on the Alpha-1 Global website. Its goal is to provide tools and skills to facilitate engagement with politicians at both national and European level. For this purpose, the European Alpha-1 Awareness Day was used as an example, and Alfa-1 Spain showcased the activities they conducted in 2019. Another supporting tool announced during this webinar was the [Local Empowerment for Advocacy Development \(LEAD\) Grants](#) available for European national Alpha-1 organizations. Calls for application are open until 3 December 2019.



II. CONTEXT

The webinar built on the advocacy training opportunities conducted throughout the years by the Alpha-1 Foundation, such as the Alpha-1 advocacy training in Milan and the online [Advocacy Pathway](#). This webinar also followed the publication of the Alpha-1 Expert Recommendations in 2017 and the roundtable events, organised in the European Parliament to mark the previous two Alpha-1 Awareness Days. The webinar was also in line with the Alpha-1 priorities for 2020, which include facilitation of stakeholder collaboration, raising awareness, coordination of national Alpha-1 organizations, and promotion of early diagnosis and optimal access to care.

III. ADVOCACY AND PUBLIC AFFAIRS

During the webinar, it was explained that advocacy is supporting and arguing for a cause or policy. It is essential for any political cause or message, especially in the field of rare diseases. The Alpha-1 community faces several challenges, such as little to no awareness of the condition, late diagnosis, unfamiliarity with Alpha-1 care standards, and limited or no access to augmentation therapy. It was explained that through advocacy, these challenges can be addressed, as it provides the chance to interact with political stakeholders to showcase **the much-needed patient perspective**, which can lead to tangible political changes and relationships.

1. The Alpha-1 Advocacy Checklist

To facilitate Alpha-1 National Members' interactions with policymakers, the Alpha-1 Foundation developed the Alpha-1 Advocacy Checklist. This checklist was the main focus of Webinar's section on advocacy and public affairs. The checklist, now available on the [Alpha-1 Global website](#), enables the identification of the major steps which need to be considered when undertaking political outreach and building advocacy plans. The checklist revolves around four major steps.

a. Step 1: Develop a Work Plan

Every advocacy strategy is highly dependent on a concrete plan. Building an adequate work plan allows patient advocates to look into the current political context and ensure that the relevant stakeholders, policies, scientific developments and events are all taken into consideration. A major part of developing a work plan is to identify the goals and objectives of the outreach/campaign. The goal is the long-term desired outcome, whereas the objectives are the steps needed to reach the set goal. Based on the goal



Figure 1 - The Alpha-1 National Advocacy Checklist is available on the Alpha-1 Global website through [this link](#).

and the objective, a political ask should also be developed. **A political ask is a recommendation aimed at a political stakeholder with the objective of achieving a specific goal.** It was explained during the webinar that the specific asks for policymakers must be always concrete and realistic. Always remember that one goal can have several political asks as it might be achieved through different pathways (e.g. 1 goal – 3 pathways – 3 political asks). Moderators provided a concrete example on how to develop a political ask. The steps of the example were the following:



Figure 2 - Example of the steps taken to develop a concrete political ask

Identifying strengths and weaknesses, both one’s own and the stakeholders’, can be useful to enable planning for possible challenges and ways to overcome them. It is impossible to plan everything, but a good plan is one that is flexible and adaptable. Step 1 should thus be recurring, and the work plan should be adjusted as needed throughout the outreach process for specific stakeholders.

b. Step 2: Connect with the Relevant Stakeholders

Identification: Identifying relevant stakeholders depends on national context. However, there are a few routes which can be explored in every national scenario – i.e. National parliaments are often composed of different committees including a health or a social one; members of national parliaments often table written questions or participate in political debates – information which is easily consultable on national parliaments’ websites; events on COPD and other overarching themes relevant for Alpha-1, such as climate change and air pollution also offer opportunities for targeting stakeholders.

Connecting with stakeholders: Opportunities to connect with political stakeholders can range from attending an event, through social media, to pro-actively outreaching and scheduling a meeting. Regardless of the method, it is crucial that stakeholder engagement is supported by concrete messages, individually tailored to the specific stakeholder. Participants were encouraged to also prepare materials to share with stakeholders during meetings – e.g. Alpha-1 Expert Recommendations booklet.



c. Step 3: Follow-Up

Face-to-face meetings and social media engagement are always as effective as their follow-up activities. There are many different ways to ensure an adequate follow-up. Sharing successful meetings and events on social media and tagging the stakeholder in question is crucial to maintain their interest. After a meeting or an event, a thank-you e-mail must be sent. This can be subsequently followed by different updates from the Alpha-1 patient community to start a meaningful professional relationship. Staying in touch can be key to building a real partnership.

d. Step 4: Participate in a Truly European Awareness Day

In order to raise awareness as much as possible, participants were encouraged to engage with the social media campaign around the European Alpha-1 Awareness Day. This will inevitably strengthen the Alpha-1 messages, especially if links are created with activities at national level. The European Alpha-1 Awareness Day can strengthen the voice of the Alpha-1 community and show the real scope of the challenges faced. It can also be a platform to spread the Alpha-1 messages by organising activities and events, posting articles and news pieces, and engaging with the planned Alpha-1 Social Media plan. There is a strong correlation between European and national level politics, where one feeds into the other. Therefore, coordinated action can lead to a more effective communication of the needs of the Alpha-1 community.

2. The 2020 European Alpha-1 Awareness Day

a. Context

In 2018 and 2019, Alpha-1 Global marked the EU Alpha-1 Awareness Day in the European Parliament through roundtable discussions. In 2018 national representatives discussed specific challenges throughout Europe.



Among others, one of the common asks was the establishment of specialized medical centers and centers of reference. It was specified that at EU level there is a need to allow and ensure good quality cross-border healthcare. The 2019 roundtable on *the Importance of timely diagnosis and sharing expert knowledge across Europe* saw discussions referring to improving the implementation of the European Reference Networks (ERNs). It was noted that this will strengthen the Alpha-1 community and allow improvements in collaboration between stakeholders. There was therefore a call for better integration of ERNs into national health systems. The 2020 European Alpha-1 Awareness Day will build on these past experiences. It was announced that amongst current topics being considered is the follow-up on “Challenge 3: Coordination” from the Alpha-1 Expert Policy Recommendations – “*The development of an “EU Stamp”, recorded on the Orphanet database denoting a centre of excellence by disease area.*



This stamp would be the same processing form for ERN applications and comparatively applicable for patients to know where they will receive expert care.”

b. Importance

During the webinar, it was stressed that the European Alpha-1 Awareness Day provides a great opportunity to raise awareness and follow-up on the concrete recommendations of the Alpha-1 community. It is ideal to show a united front in spreading the message of Alpha-1. The goal of the Awareness Day is not just to temporarily increase attention for Alpha-1, but rather to make a lasting impact. The European Alpha-1 Awareness Day 2020 aims to result in a Call to Action that is endorsed by different political stakeholders and which can ultimately be used to improve policies for Alpha-1 patients.

c. Alfa-1 Spain

Martiño Suarez explained that Alfa-1 Spain has been highly active in the 2019 European Alpha-1 Awareness Day. They have used their activities as opportunities to raise public awareness, increase patients' visibility and awareness of the current situation of Spain, where there is a high incidence and low diagnosis. The activities have also served to demand better diagnosis and to further involve the medical and researcher community in jointed initiatives. Mr. Suarez added that Alfa-1 Spain managed to have the involvement of 50 volunteers and 3 doctors and researcher teams, across 18 hospitals throughout Spain. They also distributed around 5,000 booklets. This resulted in TV coverage, at national, regional and local levels. It also led to ample coverage on local radio, in the press, and on social media.



Día europeo del Alfa-1, una enfermedad rara que sufren muchas personas sin saberlo

Figure 4 - Example of an article on the activities of Alfa-1 Spain for the European Alpha-1 Awareness Day, which can be accessed through [this link](#).



3. Social Media Campaign

It was announced that a social media campaign will be developed for the 2020 European Awareness Day. This is a way to reach a larger audience and to truly take advantage of Alpha-1's global network. Participants were encouraged to engage with the social media campaign and stay in touch with contacts and followers. It was noted that in order to amplify the weight of social media engagement, patient representatives should consider using visuals/photos and banners in their social media posts. Social media provides a great platform to make the message unique by sharing personal stories. Arguably the most important aspect of a successful social media campaign, is coordination between own accounts but also between other



alpha-1 organizations. To stay updated, please follow [Alpha-1 global](#) and the [Alpha-1 European Awareness Day](#) on twitter.

IV. QUESTIONS AND ANSWERS

During the Questions and Answers session, several topics were discussed:

- **When to engage in advocacy activities?**

It was explained that the right timing to engage in advocacy depends on the objectives and the goal. For example, when the objective is linked to a specific politic file, the timing is quite clear. In other cases, it also depends on the level of awareness of the stakeholders.

- **What are examples of typical mistakes one can make in advocacy?**

Contacting politicians without a specific political ask in mind was mentioned as one of the most common mistakes in advocacy. It is a missed opportunity as politicians, while sympathetic, may not understand how they can play into the picture. Another common mistake that can be avoided through preparation is failing to look into the background of a potential stakeholder and misunderstanding their interest and knowledge.

- **Are there opportunities for advocacy in times of political instability?**

In times of political instability or the absence of a government, advocacy and public affairs strategies may depend more on EU-level action. However, this national political inertia may prove as an opportunity to prepare a more detailed strategy.

- **How essential is coordination in advocacy?**

It was also mentioned that coordination is indeed key, and action should focus on where it is possible to make a difference. Some campaigns could have detrimental effects on others, and it is therefore always good to have a wider overview of ongoing action.



V. CONCLUSION

It was concluded that patient advocacy is an essential part of the political landscape, and can positively affect patient outcome. The more united and coordinated the community is, the stronger the impact of the messages and the more positive impact can be achieved. The advocacy checklist can serve as a basis to maximize the effectiveness of advocacy and public affairs strategies. The goal of using advocacy and public affairs for Alpha-1 patients is to improve the situation of Alpha-1 patients and to address the most urgent



problems they face. Coordinated action is an essential aspect of increasing the impact that can be made patients. It is for this reason that the 2020 Awareness Day should be truly European.

VI. LIST OF REGISTERED PARTICIPANTS

- **Agnieszka Bakula**, *doctor*
- **Alejandro Gardie**, *Grifols*
- **Aline Mola**, *RPP Group*
- **Andrew Deans**, *NHS Lothian*
- **Annika Warm**, *Alfa-1 Sweden*
- **Cori Warren Ruktanonchai**, *Alpha-1 UK Support Group*
- **David Parr**, *NHS*
- **Estrella Drobnic**, *Grifols*
- **Giancarlo Pinero**, *Alpha-1 Foundation*
- **Graham Dalton**, *Alpha-1 UK Support Group*
- **Heleen J. Groen**, *Stichting Alpha-1 Nederland*
- **Ilaria Ferrarotti**, *Center for Diagnosis of Inherited Alpha1-antitrypsin Deficiency Dept of Internal Medicine and Therapeutics Pneumology Unit IRCCS San Matteo Hospital Foundation University of Pavia*
- **Joanna Chorostowska**, *Polish Foundation for Patients with AATD; National Institute of Tuberculosis and Lung Diseases*
- **Joelle Khraiche**, *CSL Behring*
- **José María Hernández Pérez**, *Hospital General de La Palma*
- **Karen O'Hara**, *Alpha-1 UK Support Group*
- **Ligia Puiu**, *Hospital Of Pneumophthisiology*
- **Lindsay Jarrett**, *Alpha-1 UK Support Group*
- **Marion Bouchecareilh**, *INSERM*
- **Marius Constantin Ene**, *Asociatia Alfa 1 Romania*
- **Martiño Suárez**, *Asociación Alfa-1 España*
- **Michael Wilken**, *Deutsche Patientenliga Atemwegserkrankungen DPLA e.V.*
- **Randel Plant**, *Alpha-1 Foundation*
- **Renate Shashoua**, *Verein Alpha-1 Schweiz*
- **Riccardo Ronzoni**, *University College of London*
- **Robert Durlik**, *Stowarzyszenie na rzecz osób z niedoborem alfa-1 antytrypsyny*
- **Shane Fitch**, *Lovexair Foundation*
- **Timm Greulich**, *Philipps-University Marburg*
- **Victor Gascon Moreno**, *Lovexair Foundation*
- **William Moore**, *Mereo BioPharma*
- **Wills Hughes-Wilson**, *Mereo BioPharma*
- **Yordan Aleksandrov**, *RPP Group*

