

# ALPHA-1 SOCIAL MEDIA TOOLKIT 2020



## About this Toolkit

This toolkit aims to guide communications about Alpha-1 with a particular focus on the European Alpha-1 Awareness Day 2020. It emphasises the importance of the use of social media, and includes practical examples of how to plan, conduct, and track a successful social media campaign.

## About the Alpha-1 European Awareness Day 2020

The European Alpha-1 Awareness Day takes place yearly on 25 April and is generally dedicated to raising awareness of this rare genetic condition. By doing so, it aims to contribute to improving early diagnosis, treatment and knowledge of the disease among policymakers, health care professionals and patients. Both in 2018 and 2019, this day was marked in the European Parliament through a roundtable discussion. On both occasions, the need to improve European Reference Networks and better integrate them with national health systems was underlined. As a part of the European Alpha-1 Awareness Day 2020, a roundtable at the European Parliament will build on previous years' efforts and lead to a Call to Action endorsed by multiple stakeholders.



## Key role of social media

Social media represents a unique opportunity to reach a large audience. According to Eurostat, 56% of people aged 16-74 were users of social networks in 2018<sup>1</sup>. Among younger people (16 to 24 years old), this proportion increased to 88%, meaning almost 9 in 10 people had at least one account. The use of social media can strength the understanding of Alpha-1 messages by showcasing the real scope of the challenges faced by patients, health care professionals and policymakers and their wide-reaching implications for the Alpha-1 community. Social media can also be used to connect activities and events, and to post targeted articles and news pieces to raise awareness. 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.

**Tailor your message to your intended audience**



**Examples of social media:**

**Twitter, Facebook, Instagram, LinkedIn, Snapchat, Pinterest**



<sup>1</sup> Eurostat (2019), European Commission: Are you using social networks?, accessed in February 2020 via <https://ec.europa.eu/eurostat/web/products-eurostat-news/-/EDN-20190629-1>



## Campaign Goals



This campaign aims to:

- Raise awareness of Alpha-1 among patients, healthcare professionals and policymakers. **Increased awareness** will lead to greater calls for faster diagnosis, better treatment of patients and more knowledge about Alpha-1. Through the sharing of personal journeys on social media, knowledge of the condition and the struggles faced by the patient community can reach a wider audience.
- Emphasise the **wide scope** of Alpha-1 priorities. Through the participation of different types of stakeholders in the campaign, we can better illustrate how the specific political asks of the Alpha-1 community are aligned with the priorities of a variety of stakeholders as well (e.g. clean air, strengthened health systems, other rare disease patients).
- **Encourage, broadcast, and connect** different activities for the European Alpha-1 Awareness Day.
- Create a permanent social media campaign that leads to the **systematic sharing** of messages about news, policy developments and events relevant for Alpha-1.

## Suggestions on how to engage with the social media campaign

- Engage with other Alpha-1 organisations' social media, such as Alpha-1 Global.
- Identify relevant stakeholders to engage with, such as other rare disease patient organisations, medical organisations, research and development centres, and relevant politicians.
- Address patients and the general public in your posts.
- Follow the hashtag (#Alpha1AwarenessDay).
- Contact local media to further spread the messages.
- In order to increase the audience reached by the social media campaign, it is important to connect as much as possible with policymakers. Policymakers tend to have high numbers of online followers, meaning that their messages about Alpha-1 can greatly increase awareness among online communities.
- An additional way to make the social media campaign as effective as possible is by posting video messages from policymakers. In such video messages, policymakers can communicate the importance of tackling the issues faced by the Alpha-1 community. These messages can be a clear and concise way of delivering key messages, while also increasing the exposure of the policymaker.



**Translated messages reach a wider audience**

## Messages of the Alpha-1 community

**Despite national differences, there are general priorities that are shared by the broad Alpha-1 community, which cover a wide range of areas:**

- Raise Alpha-1 awareness within the general population, which can be done by compiling and sharing national and European information, such as the Alpha-1 Expert Recommendations.
- Improvement of stakeholder collaboration in order to facilitate the promotion of patient interests and allow for growth of the Alpha-1 patient, research, and physician community.
- Inform the national/European Alpha-1 community of developments in research and patient care worldwide.
- Promote early diagnosis and optimal access to care. This can also involve monitoring of Alphas and their medical journey, as well as encouraging patient involvement in political processes.



## Step by step guide on specific social media actions



- Follow websites and social media of stakeholders such as Alpha-1 patient organisations. Consult weekly, comment, like and share.
- Create a list of challenges/issues specific to your country and align with the above-mentioned messages. This can be used to better tailor your communication strategy.
- Identify relevant stakeholders. Label three different categories of stakeholders: ones you already know, ones you want to know, and ones you should know. For example, research members of Parliament and national government, participants and speakers of relevant events. Don't forget to check local media articles.
- Engage with these targeted stakeholders via social media by responding to relevant posts they have recently made, or making targeted posts and tagging them.
- Make use of your personal networks to increase engagement and spread the messages.
- Actively participate in related upcoming events. Post about them, share photographs and tag stakeholders you have met in said events.

**If you are unable to implement these strategies, you can still engage your audience by retweeting**

## Best Practice Tips

- Target your tone, message and content to the desired audience. If multiple audiences can be targeted, do not hesitate to create several posts on the same subject. Keep in mind the extent of knowledge about Alpha-1 among your audience and emphasise the information most relevant for them.
- Make your message visual by using photos or videos. Using visual tools can make your post more interesting and relateable, and can increase interaction.
- Encourage engagement with posts by asking or answering questions.
- Aim to publish with a certain degree of regularity. Create posts ahead of time and schedule their publication date. There are many online tools that aid with this process, such as Hootsuite.
- Check social media every few days. Even if posts are scheduled, this step should not be neglected, as it is important to dynamically engage with stakeholders.
- Always proofread and double-check content before posting.
- Track which posts have more likes, shares, and comments. Certain social media platforms already offer analytics, but there are many online tools you can use for this purpose. Identify what works best for your audience and tailor future posts.



**Make sure to emphasise the unique strengths of your organisation**

To stay updated, you can also follow [Alpha-1 Global](#) and the [Alpha-1 European awareness day](#) on Twitter.

For more a more detailed guide on how to successfully advocate for the cause of the Alpha-1 community, consult the [Advocacy Pathway](#) available on the Alpha-1 Global website.

