Alpha-1 Advocacy

Webinar

31 October 2019
Agenda

**Introduction**
RPP
Alpha-1 Foundation
Context

**Advocacy & Public Affairs**
Patient Perspective and Public Affairs
National Advocacy Checklist
National and European Advocacy
Questions and Answers

**EU Alpha-1 Awareness Day**
Context
Case study: Spain
2020 Awareness Day

Questions and Answers
RPP Group
A true European firm

OUR OFFICES
- Brussels (HQ) – Public Affairs EU and Belgium
- Berlin – Public Affairs Germany
- London – Public Affairs United Kingdom
- Paris – Public Affairs France
- Rome – Public Affairs Italy
- Hamburg – RPP Visual Communication
- Vienna – Public Affairs Austria
- Canberra – Public Affairs Australia
- Madrid – Public Affairs Spain
RPP patient advocacy team
Our experience serving your goals

Yordan Aleksandrov
Senior Consultant
Yordan joined RPP Brussels in 2015 following work within the European Commission and London based public affairs companies. He has been primarily working with oncology associations and rare disease patient organizations, developing and channeling their messages in the EU political sphere. Yordan is also involved in establishing and expanding informal Members of the European Parliament groups, supporting rare diseases.

Dirk Frouws
Consultant
Dirk joined the RPP Brussels office in 2019. Before becoming a consultant at RPP, he worked at the European Parliament from 2014 until July 2019, advising a Dutch MEP in the ALDE Group (now Renew Europe). During these years he focused on a wide variety of policy areas, ranging from Foreign Affairs and Security and Defence to Brexit and political developments in Italy.

Aline Mola
Junior Researcher
Aline joined the RPP Brussels office in 2019 after concluding her studies. With a bachelors in Human Biosciences and Psychology and a masters degree in Global Health, she has developed a wide variety of knowledge that allows for a multi-sectorial perspective. Aline is also involved in coordinating national and European initiatives on rare diseases.
Introduction to Alpha-1 Foundation’s role in Alpha-1 Advocacy

“Our mission is to develop a collaborative global network of Alpha-1 patient leaders, physicians, and researchers, to increase awareness, detection, and access to care for Alphas around the world.”
Alpha-1 Community Priorities 2020

**Stakeholder collaboration**
- Facilitates the promotion of patient interest
- Allows for growth of the Alpha-1 patient, research, and physician community

**Raise Alpha-1 awareness**
- Compile and report information nationally
- Increase awareness through a diversified communication strategy

**National Alpha-1 organizations**
- Keep the global Alpha-1 community informed on research and patient care worldwide
- Leadership coordination through meetings, events, and resources

**Promote early diagnosis and optimal access to care**
- Promote early diagnosis and access to optimum Alpha-1 care and treatment globally
- Monitor access to care and treatment affecting Alphas around the world
- Encourage patient involvement in policy decision-making through focused advocacy efforts
Alpha-1 Global Hubs

- Link larger A1 NGOs with smaller groups
- Mentorship programmes
- Enhance communications
- Foster collaboration
- Establish links with physician communities
- Global interactive communication
Context: Past Milestones

- **2017 Alpha-1 Expert Recommendations**
- **2018**
  - European Alpha-1 Awareness Day 2018
  - Roundtable at the Parliament
- **2019**
  - European Alpha-1 Awareness Day 2019
  - Roundtable at the Parliament
Portuguese MEP José Inácio Faria

Dutch MEP Annie Schreijer-Pierik – Proposal for a Union Act

Romanian MEP Norica Nicolai - video

Dutch MEP Wim van de Camp - video

Italian MEP Elena Gentille - video

Swedish MEP Jytte Guteland – video

Finnish MEP Sirpa Pietikäinen – video

Alpha-1 EP Roundtable 2018, hosted by Polish MEP Marek Plura

British MEP Seb Dance

Swedish MEP Jytte Guteland – video

Portuguese MEP José Inácio Faria

Dutch MEP Wim van de Camp – video

Italian MEP Elena Gentille – video

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Alpha-1 EP Roundtable 2018, hosted by Polish MEP Marek Plura

British MEP Seb Dance
Advocacy & Public Affairs
What are public affairs and advocacy and their importance?

• **Advocacy** is supporting and arguing for a cause or policy.

• **Public affairs** is building and developing an organization's relationship with stakeholders.

• Essential for good policymaking

• Strategies can include communication through:
  
  • Targeted education
  • Social media
  • Press relations
  • Community events
  • Lobbying
  • Marketing

**Alpha-1 Advocacy**

• change public opinion and policy
• improve care for Alphas
Advocacy from the perspective of a patient

- Patient voice
- Examples of how policy affected patients
  - September 2015: Alphas, caregivers, and family members met with the FDA
  - Impact: use of placebos in clinical trials = unethical
  - Patient-Focused Drug Development for Alpha-1 Antitrypsin Deficiency

- Opportunities and difficulties for patient organizations
  - “my loss of independence”
  - “misinformed prognosis”
  - “a rescue inhaler can help everybody”
  - “additional therapies need to be developed”
Advocacy Tool: Checklist

Step by Step guide

1. WHAT IS THE CURRENT SITUATION?
   - Identify the relevant stakeholders with similar interests. E.g., healthcare interest groups, policy makers, etc.
   - Identify the relevant national/regional policies that exist. E.g., screening programmes, reimbursement policies.
   - Identify the current scientific landscape regarding Alpha-1. E.g., are the screening/treatment options available in line with most recent publications?
   - Identify upcoming events that are relevant. E.g., upcoming elections.

ADVOCACY MESSAGE:

KEY OPPORTUNITIES:

QUESTIONS/POLITICAL ASKS:

Interactive

Help you identify and deliver your message in the best possible way

Action Points
Examples
Useful links

2. Alpha-1 Global, Policy Guidelines from the Advocacy Pathway, available at: https://www.alphahal.org/advocacy/matters/policy alcana1
3. Alpha-1 Global, available at: https://matters.com/alpha-1-global
Step-by-Step Checklist

Step 1: Develop a Work Plan
- Current situation
- Goal/objective
- Political ask

Step 2: Connect with the relevant stakeholders
- Meet with stakeholders
- Use social media

Step 3: Follow-up
- Use social media/news outlets
- Send follow-up e-mail
- Stay in touch

Step 4: Participate in a Truly European EU Awareness Day
- Share messages
- Hold an event
How to develop your objectives in political asks?

- A **Political Ask** is a political recommendation aimed at political stakeholders with the objective of achieving a certain goal.
- What is your desired outcome?
- What is the path to get there?

**Goal**

- Improve diagnosis and increase diagnosis rate

**Getting there**

- Increase awareness among healthcare professionals and politicians

**Political ask**

- Include Antitrypsin deficiency in the medicine curriculum

**Credibility, consistency, knowledge**
Exercise: developing a political ask

What are the things you would like to achieve at national level in your country and what could you ask to achieve them?

**Examples of goals**
- Access to care and therapy
- Research
- Development of new therapies
- Awareness and detection
- Funding
- Blood Product Safety
- Education and outreach
- Data collection
- Patient registry
The added value of stakeholders with similar interests and how to identify them

Your opinion/attitude towards the information you have thus far collected?  
Your personal story

Points of convergence

Their opinion/attitude towards the information you have thus far collected?  
Their personal story
How to work towards creating a partnership with political stakeholders?

- Outreach
- Support
- Collaboration
- Partnership

Follow-up
National advocacy and European advocacy

- European Commission
- EU Council (National governments)
- European Parliament (citizens)
- National Parliaments

Proposals
and supervision
Appointment and proposals
Implementation

Bottom-Up
Top-Down
Any Questions?
European Alpha-1 Awareness Day 2020
Goals, objectives, outcomes

- Spread your message
- United front
- Emphasis—give your argument more power
- Act out your strategy
- Raise awareness
History of the European Alpha-1 Awareness Day

2018
National-level experiences

2019
The importance of timely diagnosis and sharing expert knowledge across Europe

Social Media Campaign

Today European Alpha-1 Awareness Day and @Alpha1_EPvent raising awareness on the rare genetic disease. Right diagnosis and treatment important and should be developed as part of Member States’ plans to address #RareDiseases

Alpha-1 antitrypsin deficiency is a rare genetic condition which can make people more likely to develop lung disease. Some people may not know they have it until symptoms appear. Find out more: blf.org.uk/support-for-you #Alpha1AwarenessDay
2020 European Alpha-1 Awareness Day

EU Cross-border Healthcare Directive

2011

Feb: Discussion of the directive in the European Parliament

2019

Jun: Court of Auditors’ Special Report on the Directive

1. Challenges in ensuring financial sustainability and effectiveness of ERNs
2. National support is imperative
3. No official evaluation

2020

Potential opening of the BTC legislation

ERN Official Evaluation Planned

2020-2023

Alpha-1 EU Awareness Day: Truly European

Call to Action!

Challenge 3: Coordination

The Call to Action
- Implement EU Cross-Border Healthcare Directive to support the right of patient to get the best possible care, also abroad, if deemed appropriate.
- The European Commission should incorporate a project under the 3rd Health Programme generating an Alpha-1 centre of excellence accreditation.
- 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.

Alpha-1 Expert Recommendation

2017
Further possibilities at national level

• Different European countries and context, but similar issues

  Little to no awareness of the condition
  Late diagnosis, while health deteriorates
  Physicians unfamiliar with Alpha-1 care standards
  Limited or no access to augmentation therapy

• EU-level efforts *alongside national level activities.*
European Alpha-1 Awareness Day, 2019

SPANISH ALPHA-1 PATIENT’S ASSOCIATION
Aims of the programme

① Raise public awareness.
② Increase visibility of patients.
③ Make aware health professionals: high incidence and low diagnosis of A1AD in Spain.
④ Demand better diagnosis.
⑤ Involve medical and researcher community in activities promoted by patients.
Keys

Key 1  Goal: involve patients  Imply as much volunteers as possible in as many cities as possible

Key 2  Goal: involve hospitals  Involve the hospitals of the patient´s cities of origin

Key 3  Goal: involve healthcare professionals and researchers  Obtain their support for the Awareness Day

Key 4  Goal: achieve impact (media and social media)  Communication Plan (online & offline)
EXECUTION

- Funding
- Patients
- Doctors & Researchers
- Media and Social Media
- Project
- Email, social media, newsletter
- Email, newsletter, phone calls
- Content programme
- Press calls & releases
- Industry
- Hospitals
- A1E social media & web
MATERIALS
RESULTS (1)

① 50 volunteers & 3 doctors and researchers teams involved
② 18 hospitals
③ 5,000 booklets
RESULTS (2)

1. Great impact on TV: national, regional and local.
2. Good impact on radio: local
3. Good impact on printed and electronic press
4. Great impact on social media
THANK YOU!
How to set up your own activity for the European Alpha-1 Awareness Day?

- What activities could you realistically organize?
- Who could you invite?
- What impact would you expect these to have?

Possible activities:
- Parliament event
- Lecture/workshop
- Community lunch with policymakers
- Disseminate recommendations in a healthcare setting, etc.
- Write and publish articles

Share your message
Social Media Campaign

*Alpha-1 global advocacy pathway: social media
Thank You
For your attention!
Any questions?
Our contact

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