



Advocacy Toolkit

To ensure awareness and access to care
for Alpha-1 patients around the world

Table of Contents

| | |
|---|----|
| Introduction..... | 1 |
| How to Get Started..... | 2 |
| Establishing Your Advocacy Strategy and Goals..... | 3 |
| Detailing Your Advocacy Strategy and Goals..... | 4 |
| Understanding the Situation and Your Audience | 6 |
| SWOT Analysis..... | 8 |
| Developing Your Advocacy Message..... | 9 |
| Effectively Communicating Your Message..... | 12 |
| Final Steps..... | 13 |
| Appendix..... | 14 |
| Sample Legislative Support Letter..... | 18 |
| Sample Thank You Letter..... | 19 |
| Sample Legislative Support Request Letter..... | 20 |

Introduction

What is Alpha-1?

Alpha-1 Antitrypsin Deficiency (Alpha-1) is a rare genetic condition which may result in serious lung disease in adults and/or liver disease in children and adults. As Alpha-1 communities join forces globally, our advocacy efforts to obtain better access to care will be served worldwide. To accomplish these goals we will align closely with governments, industry, and health and research organizations in various countries.

Alphas worldwide experience many of the same problems:

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

As a result, quality of life suffers greatly.

The challenges of obtaining the appropriate medical care vary by country. Many countries have already faced these hurdles and made progress in the areas of awareness, detection, health management, access to therapy and reimbursement. While countries have different governance structures and healthcare systems that demand a unique approach to advocacy, much can be learned from the experience of Alpha-1 communities that have faced these same challenges and won some hard fought battles.

The purpose of this document is to provide national patient organizations with some practical guidance to improve the effectiveness of these government relations. Note that suggestions may be very effective in some countries but inappropriate or even damaging in others. Readers must decide which recommendations are relevant given the political, social and cultural context in their particular country.

Alpha-1 Global is available to share resources wherever possible, and this document will be updated as needed.

We thank the Alpha-1 Foundation, IPOPI, CSL Behring and Grifols for assistance with the development of this tool.

Gonna Gutierrez, Alpha-1 Global Director
Alpha-1 Global Steering Committee
August 2015



How to Get Started

What is Advocacy and Why is it Important?

Advocacy is how individuals and organizations inform and influence the policymaking process. Legislators (or members of parliament) and regulators often are not adequately informed on issues that matter most to you. You are the expert, and have a right and responsibility to educate those making decisions affecting you and your community.

This Advocacy Toolkit aims to help you to build a successful advocacy strategy. You will find tools to engage and educate decision makers in your country or region. Included are worksheets, tips and tools that will assist in:

- Establishing your advocacy goals and strategy.
- Understanding the situation and your audience.
- Developing your advocacy message.
- Effectively communicating your message to legislators and other officials.
- Final steps to solidify success.

Establishing Your Advocacy Goals and Strategy

No one knows better than you the impact this disease has on you and your family members. That being said, it is important to realize that developing and delivering your advocacy message is a process.

The first step is to really understand what you want your communication to accomplish and the resources it will take to get it done. Establishing your goals and objectives will increase your effectiveness and success rate. The Alpha-1 Community has many agenda items:

- Access to care and therapy
- Research
- Development of new therapies
- Awareness and detection
- Funding
- Blood product safety
- Education and outreach
- Data collection and patient registry

Each of the agenda items can be accomplished in a number of ways and those paths will help you determine your goals and objectives, as well as the best strategy for success.

Just having a goal is not enough to bring the outcome you want. Like so many things in your life and certainly in your disease management, careful preparation can be the differentiating factor in any path you take to reach a goal. Understand the scope of your goal, the time you have to accomplish it and any given resources that are required to help you develop a sound strategy to accomplish your objective. This takes careful consideration and the questions on the next page help to set up the necessary evaluation and thought process.

Establishing Your Advocacy Goals and Strategy

What is your main purpose/goal for doing this?

Important Questions to Ask Yourself

| | | |
|-----|---|--|
| 1. | How much time do I have to dedicate to advocacy each month? | |
| 2. | What issues have been important to me in the past? | |
| 3. | What are the one or two most important issues to focus on over the next six months? | |
| 4. | Is there any pending legislation of interest to me or my community? | |
| 5. | Do I have my story ready to go? | |
| 6. | Do I have any other connection to my legislators? | |
| 7. | When are they in session? | |
| 8. | Are there upcoming community meetings for me to participate? | |
| 9. | Are there any upcoming committee meetings for me to engage? | |
| 10. | Does my organization have any upcoming events to invite my legislator? | |
| 11. | What advocacy effort can I get involved with through my organization? | |
| 12. | Other questions? | |

Detailing Your Advocacy Goals and Strategy

The answer to the questions on the previous page will help you determine an appropriate advocacy plan and one that is actionable and realistic. We recommend planning in six-month increments in efforts to ensure that your resources and targets are still applicable.

While this Advocacy Toolkit will focus on having an effective face-to-face meeting with your audience, it's important to consider many avenues of engagement and use them in your six-month advocacy strategy as well.

Examples of Opportunities for Engagement

- Request a face-to-face meeting (Sample Meeting Request Letter).
- Follow your legislators on Facebook, Twitter, blogs, and other social media.
- Send patient organization information and/or your personal story with a specific goal in mind. (newsletters, photos, personal story)
- Write a letter of introduction that includes your personal story.
- Write a letter about an issue of concern to you and your community. (What are you trying to gain additional support for?)
- Write a letter requesting support of legislation that impacts Alpha-1 patients. (Sample Legislative Support Letter)
- Write a thank you letter for support of an initiative that is important to you and your community. (Sample Thank You Letter)
- Invite legislators to community and patient organization events.
- Send an email summary of articles important and relevant to your patient group or organization.
- Serve as a resource to legislators on issues where you have expertise.
- Attend community events and introduce yourself to your legislator.

What is your personal or organization's goal(s) and objective(s) for advocacy?

Detailing Your Advocacy Goals and Strategy

Ensure that you are well prepared for each action item. Working with others and gaining guidance from the Alpha-1 Global Steering Committee will be instrumental in your advocacy efforts.

| Month | Action Item | Purpose | Deliverables & Next Steps |
|----------------------|--|--|---------------------------|
| Example: November | Follow my legislator on Facebook and Twitter to develop my personal story. | Use social media to learn about my legislator's interests and upcoming events. | Attend an upcoming event. |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |

Understanding the Situation and Your Audience

Understanding the Situation and Your Audience

It's vital that you go into any advocacy effort with a firm understanding of the material, political environment and where your audience is with respect to your goals and objectives. This is referred to as 'situation analysis'; the current environment that you and your advocacy message will be part of.

With this understanding you will be better prepared to navigate roadblocks and capitalize on opportunities you will encounter while implementing your strategy. In fact, this process will help you go back and make your strategy even more robust.

The process is best accomplished with a simple SWOT analysis, evaluating "Strengths, Weaknesses, Opportunities, and Threats". You must take yourself, the audience and the environment into consideration.

The exercise will help you understand the good and the bad of your current situation:

- Where you are in your readiness to discuss and your personal buy-in on your objective?
- Do you need to get additional information to fully understand the topic. If so, where do you find it?
- Do you anticipate any resistance to your message?
- Who is your audience and where are they in their buy-in with your objective?
- What communications channel will work best to deliver your message to the audience?

Understanding the Players

| Name | Committee Membership | Prior Decisions on <hr/> (Your Agenda) | Initiatives They Align With | Personal Interests or Family Hardships |
|---------------------------|----------------------|---|-----------------------------|--|
| (Person at the Top) | | | | |
| (Person They Rely On) | | | | |
| (Rare Disease/Disability) | | | | |
| (Blood Product Safety) | | | | |
| (My Connections) | | | | |
| Other | | | | |

Understanding the Situation and Your Audience

Ensure that you are well prepared for each action item. Working with others and gaining guidance from the Alpha-1 Global Steering Committee will be instrumental in your advocacy efforts.

Important Considerations

| | | |
|---|--|--|
| 1 | If your country has a federal system, what level of government—national, or state or municipal—is responsible for dealing with your request? | |
| 2 | What are the rules governing payment of medical services? | |
| 3 | What are the different systems, including universal healthcare, private insurance, the military sector and others, subsidized? | |
| 4 | Who is the person that can make the change I am advocating for? | |
| 5 | Is there an official in charge of rare disease treatment decisions? Disability? Employment? Taxes? | |
| 6 | Is there an official who handles plasma procurement or purchase? Plasma safety? | |
| 7 | Who do they rely on for information? (This will often be the one you meet with.) | |
| 8 | Do I have any connection to them through people I know? | |

SWOT Analysis

SWOT Worksheet

The information determined before will help to comprehensively evaluate the current situation and the potential roadblocks and opportunities associated with your goal.

The key is to understand how to deliver the message and the appropriate team/individual to do so. Careful and honest consideration of your organization's internal abilities and where the necessary expertise resides (or doesn't) is important. It is also vital to understand the external factors you will encounter in your advocacy effort. Not everything is in your control, but you will benefit from understanding what those factors are and how to frame your message around them.

Putting the information into a SWOT analysis will allow you to frame your message in the manner that is most appropriate while addressing particular audience.

| | Favorable | Unfavorable |
|-----------------|--|--|
| Internal | Strengths | Weaknesses |
| | What are your (or organization's strengths)? What do you do better than others? What resources do you possess? What do others perceive as your strengths? | What are your (or organization's) weakness? What do others do better than you? What can you improve given the current situation? What do other perceive as your weakness? |
| External | Opportunities | Threats |
| | What trends or conditions may positively impact you? What opportunities are available to you? | What trends or conditions may negatively impact you? What are others doing that may negatively impact you? |

After the analysis done above and firm commitment to your goal and strategy, you are well positioned to develop an effective advocacy message and push your objective forward.

Developing Your Advocacy Message

Developing Your Advocacy Message

A national Alpha-1 organization will usually get only one opportunity to present its case to government officials. Therefore, it is extremely important to take the time necessary to prepare your message well. While the benefits of improved care for people with Alpha-1 are obvious to those who live with it every day, this is not the case for government officials who may know very little about the condition. More importantly, governments have many challenges in improving the health system. Some problems affect a much larger percentage of the population. It is your responsibility to make a convincing argument that improved care for Alphas is not only a benefit to those directly affected, but also provides benefits to the country as a whole. This “win-win” situation is the outcome of your messaging. If successful, your goals and objectives will be viewed as a solution to a government’s healthcare, fiscal, or social problems.

The following Message Development Tool is designed to help you create a message that will motivate your listeners to move forward with your requested actions. The tool will help you be clear, concise, listener focused and action-oriented; leading to agreement, action and ultimately contributing to you final objective.

TIP: Credibility, consistency and knowledge base will be paramount in getting your message heard.

- Credible means you take ownership of your feelings and actions related to the message. Telling your story and stating how you feel about the issue builds credibility.
- Consistency means that you are able to maintain straightforwardness in your preparation, delivery of, and interaction with others about your message.
- And, of course, know your facts.

TIP: When preparing for a message development session, you must identify the people who should participate. It’s critical to get the right people around the table.

These are people that:

- Know the most about the topic.
- Will be communicating the message.
- Understand your audience(s).

TIP: Be sure to give careful consideration of any opposition you may receive.

- Recognize that it is a valid concern, but you think you can put their mind at ease.
- Focus on the benefits and “what keeps them up at night”.
- Respond with facts.

This planning will allow you the diversity to deliver a wide variety of information and perspectives.

Developing Your Advocacy Message

Message Development Tool-1

1. Goals and Objectives

- Access to care and therapy
- Research
- Development of new therapies
- Awareness and detection
- Funding
- Blood Product Safety
- Education and outreach
- Data collection and patient registry

2. Desired Outcome

What is your desired outcome (the ask—the path to reaching your objective)?

3. Point of View

What is your opinion or attitude toward your information and why do you feel this way—use your story (assume the official has no information about Alpha-1).

- Why is the Alpha-1 community unique?

4. Audience Acknowledgment

Use your analysis to identify characteristics that would be important to acknowledge to ensure that your message hits home—make it listener focused.

Also Evaluate:

- Prior decisions
- Initiatives they align with or are accountable for
- Their personal hardships (be careful here)

Developing Your Advocacy Message

5. Action Steps

General Action: What action do you want the listener to take during your delivery.

- Use your Alpha-1 knowledge—regional data, fast facts

Specific Actions: What action(s) do you want your listeners to take as a RESULT of your communication (how they will specifically contribute to your objective)

- Fund, support, meeting at a higher level (refer to paths).

6. Benefits

What are the benefits of them taking the “general” and “specific” actions?

- Medical
- Social
- Financial

Final Flow of Message

| | | | | |
|----------------------|-----------------------------|-----------------------------|-------------------------|----------------------|
| Welcome/Intro | | | | |
| 1. Welcome | | 2. Subject (Agenda) | 3. Goals and Objectives | |
| Opening | | | | |
| 4. Point of View | 5. Audience Acknowledgement | 6. Action Steps | 7. Benefits | 8. Key Point of View |
| Body | | | | |
| Key Point 1 | | Support (facts) | | |
| Key Point 2 | | Support (facts) | | |
| Closing | | | | |
| 8. Key Point of View | 4. Point of View | 5. Audience Acknowledgement | 6. Action Steps | 7. Benefits |

After the analysis is complete and you have developed a firm commitment to your goals and strategy, you are well positioned to develop an effective advocacy message and push your objectives forward.



Effectively Communicating Your Message

Effectively Communicating Your Message

You have spent a lot of time and effort developing a message that will be effective in motivating officials to support your requests. It is vital that it is delivered effectively and that takes some preparation in itself. There are some important “Advocacy DOs and DON’Ts” to be aware of:

DOs

- If appropriate in your country, take the lead in the meeting.
- Present your dossier as planned.
- Focus on your goals and key points.
- Focus on the future rather than dwelling on the past.
- Be constructive. Don’t just complain.
- Be clear but brief when presenting your arguments/benefits.
- Stick to the roles assigned.
- Respect the time allotted to you.
- Take notes of key points discussed.
- Be sure to capture action items.
- Take note of any specific follow-up information you have promised.
- Be polite, yet firm.

DON’Ts

- Do not get side-tracked on minor issues.
- Do not argue about facts. Present your ‘benefits’ as their solutions.
- If at all possible, do not let the legislator take over the meeting to discuss issues important only to him/her.
- Do not lose track of time.
- Do not make promises you cannot keep.
- As always, the last minute details can make or break your credibility and how well you are perceived in your readiness and expertise. This initial perception can be the difference between success and failure of your team’s efforts.

Here are few vital things to put on a pre-meeting check list to avoid last minute pitfalls:

- Rehearse, rehearse, rehearse.
- Confirm meeting time with the official’s office.
- Confirm the amount of time you will have.
- Get a final list of officials who will be attending.
- Have a pre-determined and strategic seating chart.
- Ensure your organization’s experts are still available.
- Print and package a dossier and handouts.
- Confirm that your data is the most up to date.
- Check that props and tools have been created and are in place.
- Confirm transportation and meeting location with your team.
- Exchange contact information for last minute details, changes and emergencies.

Final Steps

Final Steps to Solidify Your Message is Delivered

Finally...deliver your message. You are ready and have built the best team. You are the expert of this disease and have done your homework. Your patience and persistence is about to pay off.

The live meeting is the most anxiety-ridden portion of any advocacy strategy, but the efforts don't end there. You have to remember that the officials hear many cases and pleas. You have to make the Alpha-1 message stand out. The tips given earlier on credibility, consistency and knowledge base play a key role here.

The team should have a thank-you note outlined to send to each session's individual attendees, long before the actual session starts. The differentiating factor will be utilizing a team debrief to ensure that the note keeps the official(s) thinking about the goals and objectives of the Alpha-1 community.

The debrief should address:

- Action items.
- Information requests.
- Promises made.
- Any opposition that remains.
- Success of the meeting (buy-in, confirmed actions).
- Any new personal connections.
- Related efforts that were discussed.

Thank-You Note

After the debrief, the thank-you note should be reviewed and any of the pertinent content from the debrief should be added. The content should cover:

- Your appreciation for the meeting.
- A summary of the key points.
- The main points of agreement.
- Confirm the actions to be done by your organization.
- Statement of your organization's expectations for them.
- The information that you agreed upon in writing.

Finally, if the meeting was a success and there has been positive action in response to your request(s), be sure that it is celebrated and attention is drawn to the action and the official involved. Praise goes a long way to furthering collaboration and successes are attractive to other policy makers.

Potential avenues include:

- Phone the official(s) and personally thank them
- As appropriate, phone the official(s) supervisor
- Write and official letter of thanks with detailed impact of the action
- Publicly recognize the action and the official's contribution to the Alpha-1 community
- Give out awards at your functions (if appropriate)
- Public recognition in the media

Appendix

Fast Facts on Alpha-1 Antitrypsin Deficiency

What is Alpha-1?

Alpha-1 Antitrypsin Deficiency (Alpha-1) is a genetic (inherited) condition – it is passed from parents to their children through their genes. Alpha-1 may result in serious lung disease in adults and/or liver disease at any age.

For each trait a person inherits, there are usually two genes; one gene comes from each parent. People with Alpha-1 have received two abnormal alpha-1 antitrypsin genes. One of these abnormal genes came from their mother and one from their father.

The abnormal Alpha-1 genes

There are many types of abnormal alpha-1 antitrypsin genes. The most common abnormal genes are called S and Z. People identified with Alpha-1 most commonly have two Z genes (ZZ). Normal genes are called M. A person who does not have Alpha-1 will have two M genes (MM). Another deficient gene combination is SZ, although people with this gene combination are less likely to get lung or liver problems than those with two Z genes.

Alpha-1 occurs when there is a lack of a protein in the blood called alpha-1 antitrypsin, or AAT. AAT, the alpha-1 protein, is mainly produced by the liver. The main function of AAT is to protect the lungs from inflammation caused by infection and inhaled irritants such as tobacco smoke. The low level of AAT in the blood occurs because the AAT is abnormal and cannot be released from the liver at the normal rate. This leads to a build-up of abnormal AAT in the liver that can cause liver disease and a decrease of AAT in the blood that can lead to lung disease.

The most common signs and symptoms of disease caused by Alpha-1

Symptoms related to the lung:

- Shortness of breath
- Wheezing
- Chronic bronchitis, which is cough and sputum (phlegm) production that lasts for a long time
- Recurring chest colds
- Less exercise tolerance
- Asthma that can't be completely reversed with aggressive medical treatment
- Year-round allergies
- Bronchiectasis

Symptoms related to the liver:

- Unexplained liver disease or elevated liver enzymes
- Eyes and skin turning yellow (jaundice)
- Swelling of the abdomen (ascites) or legs
- Vomiting blood (from enlarged veins in the esophagus or stomach)



Appendix

Who gets Alpha-1 lung or liver disease?

- Alpha-1 has been identified in nearly all populations and ethnic groups.
- People with Alpha-1 may remain healthy throughout their lives. Early diagnosis and avoiding risk factors, such as cigarette smoking, can help prevent Alpha-1 from causing disease.
- Alpha-1 can lead to lung destruction and is often first diagnosed as asthma or smoking-related Chronic Obstructive-Pulmonary Disease (COPD).

Alpha-1 cannot be diagnosed by symptoms or by a medical examination alone; you need to get a simple, reliable blood test to know for sure.

- Alpha-1 is the most common known genetic risk factor for emphysema.
- Up to 3% of all people diagnosed with COPD may have undetected Alpha-1.
- Alpha-1 can also lead to liver disease. The most serious liver diseases are cirrhosis and liver cancer.
- The World Health Organization (WHO), American Thoracic Society (ATS), and the European Respiratory Society (ERS) recommend that everyone with COPD be tested for Alpha-1.

Testing for Alpha-1

The Alpha-1 Foundation supports testing for those at risk for Alpha-1. In response to concerns surrounding testing, privacy and the benefit of an early diagnosis, the Medical University of South Carolina (MUSC), with the support of the Alpha-1 Foundation, developed a free and confidential opportunity for testing. This is a research study called the Alpha-1 Coded Testing (ACT) Study.

The Foundation also established the Alpha-1 Research Registry at MUSC to encourage research, the development of new treatments and a cure for Alpha-1. The Registry is a confidential database made up of both Alphas and Alpha-1 carriers. The Alpha-1 Genetic Counseling Center is also located at MUSC. The genetic counselor is available to provide support and information to patients, caregivers, and healthcare professionals.

Testing for Alpha-1 in Your Country

To see if Alpha-1 testing is available in your country, please visit the Alpha-1 Global website: <http://www.alpha-1global.org/advocacy>. You will find the information listed by country at the bottom of the page. On the top left corner of the same page, you can also click on your country landing page for additional contact information.

Appendix

Promote exchange of expertise and education among Healthcare Providers

Work together with government, medical specialists, and organisations such as: AATD, COPDF, APLUS in the US, PLUS in Europe, and other national or regional professional organizations for nurses and doctors involved in the management of AATD, to:

- Provide standards for basic and applied diagnostic and treatment training, with emphasis on AATD lung and liver disease, in the education programs for general practitioners and nurses.
- Integrate basic and applied diagnostic and treatment training for general pediatric and pediatric herpetologist training.
- Educate providers of internal medicine, respiratory and gastroenterology medicine.
- Develop cross country/regional initiatives to allow the exchange of expertise and education, including capacity to network and funding of visits by AATD Clinical Resource Center representatives from other regions/countries.

Detection - Focus on early diagnosis and screening

- Develop clinical diagnostic protocols to reliably identify all forms of AATD.
- Promote the development and encourage the use of simple diagnostic tests for AATD at a local level.
- Implement a system for recognition of symptomatic patients and ensure appropriate diagnostic measures.
- Ensure funding for genetic laboratory tests is available at a national level via centers of excellence.
- Promote newborn screening programs to ensure early detection.

Ensure access to treatment

- Ensure satisfactory access to treatment for people with AATD as it has been shown to provided bioavailability at site.
- Ensure that safe therapy is available to all patients who require ATT augmentation.
- Ensure satisfactory access to treatment for people with AATD as it has been shown to provided bioavailability at site of action.
- Recognize the social needs of child and adult AATD patients and their families and facilitate their access to adequate support and education services.
- Ensure the availability and high quality supply of human plasma.
- Ensure the reimbursement of orphan drugs according to their medical efficacy for the patient and not according to the price of the product.

Data collection

- Support a national AATD patient registry. Models of national registries are available at www.alpha1.org.
- Participate and fund in epidemiological studies to assess prevalence and incidence of AATD in the population.

Appendix

- Encourage the creation of and input into international registries which will enable future diagnostic processes by identifying: pattern of clinical presentation of these diseases; natural history of the various AATD (morbidity, mortality, complications); relationships between clinical disease patterns and genetic backgrounds and environment.
- Encourage transnational cooperative research and multinational clinical trials.
- Encourage the establishment of Clinical Resource Centers to promote best practice in terms of disease classification, treatment outcome measures and cost assessments of treatments.

Potential Benefits

There are many benefits for a country when it improves care for Alphas. These are some of them.

Social Benefits:

- There is much less disability among Alphas who are able to comprehensively manage their disease through access to therapy, support and lifestyle management. This avoids the social costs of caring for them.
- Disease management of Alpha-1 sustains the ability to contribute to society through active education systems and employment.
- Patient health management defers the need for full time caregiving a further depletion of the family members active contribution to society through education and employment.

Medical benefits:

- Mortality is decreased.
- The outreach efforts needed to diagnose people with Alpha-1 can be copied for use with other conditions.
- With adequate diagnosis and care, hospital admission and readmission rates can be reduced.
- The idea of comprehensive care developed for Alpha-1 can be used as a model to treat other diseases.
- The physicians in a country with a national treatment plan can receive valuable information from the Alpha-1 Foundation/Alpha-1 Global.
- A well-developed Alpha-1 care system can ensure that valuable resources are used wisely to ensure the best outcomes.
- The partnership among health authorities, doctors and patients is well-developed for Alpha-1 patients in some countries. This is a powerful concept that can be applied to other areas of the health system.

Important Data (country-specific)

Government officials need good data in order to make decisions. It is essential that any Alpha-1 representative presents the key data it possesses. This data must be accurate; otherwise your organization will lose credibility.

Sample Legislative Support Request Letter

Date: _____

The Honorable _____

RE: _____

Title of the issue

Dear _____

Share your personal story

My name is _____ and I am writing to you today to ask with your support with

Explain issue

Further explain how the legislation impacts you and your community

Highlight main objective of the legislation

Thank you for taking in to consider this important legislation that will _____, Moving forward, I ask that you keep in mind the unique needs of patients with _____ and the importance of preserving access to care and treatment in mind.

If you have any questions, please do not hesitate to contact me at _____. Thank you again for your time and consideration.

Best Regards,

Enter your contact information

Your name _____

Your address _____



Sample Thank You Letter

Date: _____

The Honorable _____

Dear _____

My name is _____ and I am writing to you today as a consultant to thank you for
Your support of individuals with Alpha-1 Antitrypsin deficiency.

**Explain how the
legislation
impacts you and
your community**

Thank you again for your support. I look forward to continuing to work with you in the future.

If you have any questions, please do not hesitate to contact me at _____.

Best Regards,

Your name _____

Your address _____

Your Contact Information

Sample Legislative Support Request Letter

Date: _____

The Honorable _____

Dear _____

My name is _____, and I am writing to you today as a constituent to ask for your support of persons with Alpha-1 Antitrypsin deficiency and request a meeting with you to discuss

Thank you for taking the time to consider this request. I will follow up with you in the coming weeks to identify a time that works best for us to meet. Please do not hesitate to contact me at

_____ should you have any further questions.

Best Regards,

Enter your contact information

Your name _____

Your address _____

Explain the issue or legislation that you are interested in bringing to the legislator's attention.

Explain your disease state and share aspects of your personal story.

Explain the issue or legislation you would like to discuss, and how it impacts you.

Include a picture with your story to help make a connection.





Connecting Our Community

<http://www.alpha-1global.org>

