

Communicating with Policy Makers

Regardless of the manner by which you communicate with your policymaker (whether it is by letter, face-to-face meeting or phone call) you should keep the following in mind.

Do's

- Be on time.
- Be courteous to both the policymaker and the policymaker's staff.
- Know something about the policymaker you are meeting with, such as: his/her background, party affiliation, hometown, and if possible, whether they are on a committee with jurisdiction over health care issues.
- Define and personalize how prior authorization would impact you. Focus on the health consequences of treatment delays. Request that your therapy be placed on the Preferred Drug List (PDL). It's about access.
- Be concise - policymakers and their staff are extremely busy and are interested in the "bottom line."
- Make sure the information you provide is accurate.
- Know what you wish to ask for prior to communicating with a policymaker -- if you don't ask, you don't get.
- Be confident and assertive in making your case, but don't dismiss opposing arguments - different views can help guide your future efforts.
- Ask for a commitment, but don't expect one.
- Make sure that you identify a staff contact with whom you can follow up.
- Remember that no policymaker can be with us 100 percent of the time - don't expect to hit a "home run" every time you meet with a legislator, Medicaid Director or other staff.
- Follow-up your contact with a letter or phone call that briefly re-states your concerns and asks for a position.
- Stay on top of the issue without wearing out your welcome.

Don'ts

- Don't threaten, cajole or berate a policymaker or their staff. This is one sure way to lose support.
- Don't be impatient. Understand that you are one of many constituents vying for a policymaker's time and attention and that there are many sides to every issue. Respect that a decision may take time.
- Don't ever ignore a request for further information. Being responsive to such a request not only observes a basic courtesy, but it gives you another opportunity to keep your name and issue under consideration.
- Don't get discouraged. Relationship building takes time.

Sample Legislative Letters

Advisory

This tab contains a number of pieces of sample correspondence addressed to state legislators and state agencies. We emphasize that this sample correspondence is intended only to provide a framework for your own correspondence and is not intended to be used word-for-word. Actual consumer correspondence should reflect each correspondent's own personal experiences and feelings. Legislators seldom respond positively to form letters, and we would not presume to suggest that we know how to adequately express your own personal thoughts about the importance of maintaining your family's timely access to plasma therapies.

SAMPLE

Sample Letter Legislative Thank You for Alpha-1

[The following letter is intended to be illustrative only. Correspondents should phrase the letter in a manner appropriate to their own circumstances.]

[DATE]

Honorable [NAME]
Chair, House [] Committee
[Office Address]
[Street Address]
[City, State, Zip]

**Re: Exemption from Prior Authorization under Medicaid for Alpha-I
Antitrypsin (AAT) Therapy for Alpha-I Antitrypsin Deficiency (Alpha-I)**

Dear Chairman [NAME]:

Thank you for meeting with me to discuss eliminating the sunset of the exemption from prior authorization under Medicaid for Alpha-I Antitrypsin (AAT) Therapy for Alpha-I Antitrypsin Deficiency (Alpha-I). I very much appreciated the opportunity to discuss this very crucial issue.

As I indicated in our meeting, it is important to me, as a sufferer from Alpha-I, that I have timely access to AAT. When I received a diagnosis of Alpha-I, I was told that nothing would repair the lung damage I had already suffered. The weekly infusions of AAT that I receive arrest, but do not reverse, my loss of lung function. In the absence of the timely application of AAT, Alpha-I tends to be relentless in the manner that it destroys pulmonary tissue. This prior authorization process could put me at risk for hospitalization, a much greater expenditure for the Medicaid program than the cost of my AAT.

It is for these reasons that I hope that you will agree to vote for legislation that will exempt AAT from prior authorization under Medicaid.

Again, thank you very much for your time and consideration on this matter.

Sincerely,

Mr. / Ms. [NAME]
[ADDRESS]

S A M P L E

Legislative Thank You Letter for Clotting Factors

[The following letter is intended to be illustrative only. Correspondents should phrase the letter in a manner appropriate to their own circumstances.]

[DATE]

Honorable [NAME]
Chair, House [] Committee
[Office Address]
[Street Address]
[City, State, Zip]

Re: Sunset of Exemption from Prior Authorization under Medical Assistance
for Anti-Hemophilic Blood Clotting Factor Therapies (last sentence of
Minn. Stat. 2566.0625, subd 13(h))

Dear Chairman [NAME]:

Thank you for meeting with me to discuss eliminating the sunset of the exemption from prior authorization under Medical Assistance for anti-hemophilic blood clotting factor therapies. I very much appreciated the opportunity to discuss this very crucial issue.

As indicated in our meeting, it is important to me, as the parent of a hemophiliac, that my child have timely access to blood clotting factor therapies. Lack of timely access to these therapies can cause severe damage to internal organs and joints, leading to skeletal malformities, excruciating pain, and premature death. Requiring prior authorization to use these therapies in order to reduce costs in the prescription drug side of the Medical Assistance program could result in even greater costs under the hospitalization and skilled nursing divisions of the Medical Assistance program. That is why I hope that you will agree to include a provision in the Health and Human Services budget that will eliminate the July 1, 2003 sunset of the prior authorization exemption.

Again, thank you very much for your time and consideration on this matter.

Sincerely,

Mr. / Ms. [NAME]
[ADDRESS]

SAMPLE

Legislative Thank You Letter for IVIG

[The following letter is intended to be illustrative only. Correspondents should phrase the letter in a manner appropriate to their own circumstances.]

[DATE]

Honorable [NAME]
Chair, House [] Committee
[Office Address]
[Street Address]
[City, State, Zip]

Re: Exemption from Medicaid Prior Authorization Procedures for
Intravenous Immunoglobulin Therapies

Dear Chairman [NAME]:

Thank you for meeting with me to discuss supporting legislation to exempt intravenous immunoglobulin (IVIG) therapies from Medicaid prior authorization procedures.

As I indicated in our meeting, it is important to me, as a sufferer from one of the more than 100 primary immune deficiency diseases, that I have timely access to IVIG therapies. When I received a diagnosis of Severe Combined Immunodeficiency (SCID), I was told that I could expect to experience a variety of recurring infections for the rest of my life. The infusions of IVIG therapies that I receive treat the infections that result from SCID, but do not cure the basic disease. Without timely treatment, every infection that I develop could become fatal. This prior authorization process could put me at risk for hospitalization, a much greater expenditure for the Medicaid program than the cost of my IVIG.

It is for these reasons that I hope that you will agree to vote for legislation that will exempt IVIG from prior authorization under Medicaid.

Again, thank you very much for your time and consideration on this matter.

Sincerely,

Mr./ Ms. [NAME]
[ADDRESS]

SAMPLE

Generic Legislative Letter for Alpha-1

[The following letter is intended to be illustrative only. Correspondents should phrase the letter in a manner appropriate to their own circumstances.]

Honorable [NAME]
Chair, House [] Committee
[Office Address]
[Street Address]
[City, State, Zip]

Re: Exemption from Prior Authorization under Medicaid for Alpha-1 Antitrypsin (AAT) Therapy for Alpha-1 Antitrypsin Deficiency (Alpha-1)

Dear [Rep./Del./Assemblyman]:

I have Alpha-1 Antitrypsin Deficiency (Alpha-1), a fatal hereditary lung disease, sometimes referred to as genetic emphysema. Alpha-1 is a single gene defect that leads to pediatric liver failure in infants and children and serious lung disease in adults. I am writing to ask that the House [] Committee amend the state Medicaid prior authorization statute to exempt from prior authorization procedures Alpha-1 Antitrypsin (AAT) Therapy, the protein augmentation therapy that is the only treatment available to stop the lung destruction associated with Alpha-1.

When I received a diagnosis of Alpha-1, I was told that nothing would repair the lung damage I suffered. The weekly infusions of AAT that I receive arrest, but do not reverse, my loss of lung function. In the absence of therapy, the pulmonary destruction of Alpha-1 tends to be relentlessly progressive.

At times, Alpha-1 can be overwhelming and frightening. Individuals like me who have the lung destruction that Alpha-1 causes have a significant loss of lung function and irreversible deterioration of lung tissue. This causes symptoms that include a severe shortness of breath and repeated lung infections, which in turn often necessitate full-time use of supplemental oxygen. Alpha-1 generally does its worst damage between the third and fifth decades of life, causing disability leading to loss of employment, frequent hospitalizations, family disorganization, and the suffering known only to those unable to catch their breath. In some cases, premature death results.

I am appealing to you for assistance on this matter, to ensure timely access to this life-sustaining therapy. I ask that the House [NAME] Committee amend the state Medicaid prior authorization statute to exempt AAT therapy for Alpha-1 from prior authorization procedures.

Thank you for your assistance on this issue.

Mr. / Ms. [NAME] [ADDRESS]

SAMPLE

Generic Legislative Letter for Clotting Factor

[The following letter is intended to be illustrative only. Correspondents should phrase the letter in a manner appropriate to their own circumstances.]

[DATE]

Honorable [NAME]
Chair, House [] Committee
[Office Address]
[Street Address]
[City, State, Zip]

Re: Sunset of Exemption from Prior Authorization under Medical Assistance for
Anti-Hemophilic Blood Clotting Factor Therapies [last sentence of Minn.
Stat. 256B.0625, subd 13(h)]

Dear Chairman [NAME]:

I am the parent of a [son/daughter] who has [Hemophilia A, Hemophilia B, von Willebrand disease]. I am writing to request that the Health and Human Services Finance Committee amend the state budget to extend the Medical Assistance exemption from prior authorization for anti-hemophilia blood clotting factor therapies.

At times, being the parent of a hemophiliac can be overwhelming and frightening. The parent of a hemophiliac must be braced for anything. Without weekly treatment with anti-hemophilia clotting factor to prevent spontaneous bleeding, my [son/daughter] can experience bleeding into [his/her] muscles, joints, or other internal organs. The symptoms of internal bleeding may not be obvious for several hours or even days following injury, and may not initially be accompanied for bumps or bruises. Over time, however, this excessive bleeding can cause severe damage to internal organs and joints, leading to skeletal malformities, excruciating pain, and premature death. Such damage can be prevented only by ensuring that the proper therapies are administered in a timely manner.

I am appealing to you for assistance on this matter not for myself, but rather on behalf of my [son/daughter]. This is about ensuring that my [son/daughter] has timely access to the lifesaving anti-hemophilic blood clotting factor therapies prescribed by [his/her] physician. We both ask that the exemption from authorization provided under Minn. Stat. 256B.0625 be extended by eliminating the sunset date provided in the last sentence of subdivision 13, paragraph (h) of that section.

Thank you for your assistance on this issue,

Mr./Ms. [NAME] [ADDRESS]

SAMPLE

Generic Legislative Letter for IVIG

[The following letter is intended to be illustrative only. Correspondents should phrase the letter in a manner appropriate to their own circumstances.]

[DATE]

Honorable [NAME]
Chair, House [] Committee
[Office Address]
[Street Address]
[City, State, Zip]

Re: Exemption from Medicaid Prior Authorization Procedures for Intravenous immunoglobulin (IVIG) Therapies Used to Treat Primary Immune Deficiency Diseases

Dear [Rep./ Del. /Assemblyman NAME]:

I have (insert disease) common variable immunodeficiency, one of 100 known primary immune deficiency diseases. Primary immune deficiencies are diseases in which the immune system is missing or compromised, causing common infections to become life threatening and debilitating. In many cases primary immune deficiencies are hereditary and therefore are vastly different from the acquired form of immunodeficiency (HIV) or secondary immunodeficiency associated with cancer therapies. I am writing to ask that you support legislation that would exempt the intravenous immunoglobulin therapy (IVIG) which I use to treat my disorder from state Medicaid prior authorization procedures.

The only effective treatment for primary immune deficiency is to replace my immune system with a plasma derived product which is infused every three to four weeks to ensure that I am protected from common infections. These infusions of IVIG contain antibodies normally present in human blood and allow me to live a normal productive life. At times, (insert disease) can be overwhelming and frightening. When I received a diagnosis of (insert disease), I was told that I could expect to experience a variety of recurring and incapacitating infections for the rest of my life. Without treatment, every infection that I develop could become fatal.

I am appealing to you for assistance on this matter, to ensure timely access to these life-sustaining therapies. I ask that you vote to support legislation that would exempt IVIG therapies from the state's Medicaid prior authorization procedures.

Thank you for your assistance on this issue,

Mr. / Ms. [NAME] [ADDRESS}

SAMPLE

Generic Legislative Letter for Single Source Provider Contracts

[The following letter is intended to be illustrative only. Correspondents should phrase the letter in a manner appropriate to their own circumstances.]

[DATE]

Honorable [NAME]
Chair, House [] Committee
[Office Address]
[Street Address]
[City, State, Zip]

Dear Senator [NAME],

I am writing to express my concerns with the provisions of HF 2028 (as passed by the Senate) that would implement a single source provider arrangement for beneficiaries in the Minnesota state-run health care programs that have hemophilia. Due to the fact that the implications of the *new* single source provider arrangements on the hemophilia community have not been fully analyzed by the legislature, I respectfully request that the provisions of HF 2028 dealing with hemophilia be removed from the bill and studied further before being reconsidered.

My late husband lived with hemophilia and the challenges HIV/AIDS and HCV presented to us as a family. For many years my husband was dependent on me to care for him, in our home. It was a labor of love. My late husband's quality of life was improved every day he could stay in our home verses being admitted to the hospital. Not only was this a quality of life issue it was an economic issue as well, our overall healthcare costs were greatly reduced by providing care for my husband in our home. Critical to providing care for *my* late husband at home were the choices available to us in respect to the provider of clotting factor therapies as well as disease management services. By virtue of choice, I was able to choose the provider that matched our unique needs as a consumer of products and services. Without this option available to us, I am not sure of the quality of life my late husband would have had, or if I would have lived up to my belief that I must try to the best of my ability to be a responsible steward of our medical expenses. Choice and access are equally important to those affected by a chronic disorder such as hemophilia to ensuring quality of life.

As currently drafted, HF 2028 (Article 21, Section 26, Subdivision 4) would require that beneficiaries in the state's Medicaid program with hemophilia obtain their life-saving blood clotting factor therapies, and disease management services from a single provider that enters into a contract with the Department of Human Services. Medicaid beneficiaries in Minnesota that have hemophilia have the ability to obtain their care, therapies, and disease management services, from the providers of their choice, as long as the providers participate in the state Medicaid program.

I believe that the current system of care has been working well and has assured that all beneficiaries in the Medicaid program with hemophilia have access to life-saving blood clotting factors and other disease management services. I do not believe that the minimal cost savings that would be realized by the state as a result of the implementation of this new arrangement is sufficient to warrant a change to the existing treatment program for beneficiaries in the

Medicaid program who have hemophilia. I believe that maintaining the ability of a hemophiliac to access the provider and blood clotting factor product of their and their physician's choice is critical to the successful treatment of this life-threatening disease. Any change to the existing program could significantly impact the quality of life for hemophiliac beneficiaries in the Minnesota Medicaid program.

Under a single source provider arrangement as is proposed in this legislation, there is a possibility that hemophilia patients will not be able to access the full range of plasma- derived and recombinant blood clotting .factor therapies. The vendor that is ultimately selected to administer the program may choose to make only certain therapies, or certain brands of therapies, .available to participants in the program. In addition, it is possible that the vendor will attempt to switch beneficiaries to less costly therapies without fully evaluating the impact of the change on the quality of care. The therapy that they are switched to may not be the therapy of their and their physician's choice, and may not be the therapy to which the individual responds most effectively.

In addition, the successful treatment of hemophilia is not only the result of the administration of life-saving blood dotting factor therapies. The life-long relationships that are built between a patient, his physician, his provider of blood clotting factor, and all others in the hemophilia care system contribute significantly to the successful treatment of this life-threatening disease. Not only do the current providers of hemophilia services in Minnesota provide life-saving blood clotting factor therapies, but they also provide a wide range of other services, such as 24-hour telephone access to disease management consultants, medical jewelry, helmets and padding, advance notice of product withdrawals and recalls, camp sponsorships, as well as advocates to address the unique issues that families living with hemophilia bleeding disorders face. I do not believe that a single provider of hemophilia services in Minnesota can provide the same assurance that personal relationships will be at the center of their program. There is no guarantee in this legislation that he vendor that is selected to administer this program will be required to make these additional services available to participants in the program. In fact, it is likely that the selected vendor will choose to not make these additional services available.

I respectfully request that you remove the hemophilia single source provider provisions from HF 2028. The hemophilia community in Minnesota would be willing to work with the legislature over the summer to fully study the implications that implementation of a single source provider arrangement could have on the hemophilia community's access to, and choice, of providers and therapies. In addition, I would appreciate the opportunity to meet with you at your earliest convenience to further discuss this legislation. I will contact your office in the near future to setup a mutually convenient time for us to meet.

Thank *you* in advance for your consideration of my request. Please feel free to contact me if you have any questions.

Sincerely,

Mr. / Ms. [NAME]
[ADDRESS]

SAMPLE

Letter to State Medicaid Directors for Clotting Factors

[The following letter is intended to be illustrative only. Correspondents should phrase the letter in a manner appropriate to their own circumstances.]

DATE

[NAME]
[Street Address]
[City, State, Zip]

RE: Plasma-Derived and Recombinant Analog Therapies

Dear [NAME]:

Plasma-derived and recombinant analog therapies ("plasma therapies") treat unique life-threatening diseases, medical conditions, and disorders, such as hemophilia, immune system deficiencies, hepatitis, Alpha-1, as well as burns and shock. I am writing to acquaint you with these therapies and to ask that you not subject plasma therapies to prior authorization under your state's Medicaid program, but instead include them on the Medicaid program preferred drug list (PDL).

I am the [mother/father] of a [son/daughter] with [a blood clotting disorder/Alpha-1/immune deficiency disorder]. I know that recent 15 percent annual increases in Medicaid prescription drug expenditures are driving total Medicaid costs higher and that, as a result, your program is considering [creating/enhancing] prior authorization procedures and creating a preferred drug list (PDL). I believe that it would be inappropriate to subject the prescription of plasma therapies to prior authorization.

State Medicaid spending on plasma therapies does not drive Medicaid program expenditures. Subjecting plasma therapies to prior authorization could compromise the timely access of Medicaid recipients to crucial treatments, while doing little to reduce overall Medicaid expenditures. The nature of plasma therapies is such that those therapies should be automatically placed on any PDL developed by the state Medicaid program.

Plasma therapies are different from the commonly advertised, compound-based pharmaceutical products, which are the target of Medicaid cost-cutting efforts. These therapies are not pills, syrups, sprays, lotions, or inhalants; they are administered through infusion. They are designed to treat highly unique, chronic diseases. They require a series of complex manufacturing steps, validation criteria, and constantly evolving viral inactivation processes to ensure safety and efficacy. In addition, for the most part, these plasma therapies are distinct, sole source pharmaceuticals that have no generic equivalents that could be substituted under a prior authorization program.

The diseases, conditions, and disorders that plasma therapies treat include the following:

- **Blood Clotting Disorders (Hemophilia):** More than 17,000 people in the United States with hemophilia have inherited a missing or low supply of the genetic factors needed for normal blood clotting. Not only may hemophiliacs experience bleeding after dental work, surgery, or trauma, they may experience bleeding in their joints or internal bleeding with no trauma or injury, and without apparent cause. Treatment to prevent this spontaneous bleeding typically requires the infusion of blood-clotting factor one to three times a week. Patients who rely on anti-hemophilic factor products need their therapies in an expedited fashion. A delay in a patient receiving his or her clotting factor product could cause long-term medical complications. Bleeds into joints can cause permanent damage and crippling, especially in children. A delay may even prove to be fatal if the patient is suffering from an intracranial or gastrointestinal bleed.
- **Immune Deficiency Disorders:** Immune deficiency diseases are disorders in which the immune system fails to properly recognize and react to invading microorganisms, leading to life-threatening or fatal infections. Primary immune deficiency diseases are a group of 50 diseases caused by intrinsic defects at the cellular or tissue level. Intravenous immune globulin (IGIV) is a solution of immunoglobulin that contains antibodies normally present in human blood. The solution is prepared from pools of serum collected from large numbers of donors and extensively processed to ensure patient safety. IGIV is the only effective treatment for primary immunodeficiency disease, and it has been proven clinically beneficial in the treatment of secondary immune deficiency diseases, such as chronic lymphocytic leukemia and HIV infection, and in bone marrow transplantation.
- **Alpha-1-Antitrypsin Deficiency (AAT):** Alpha-1-Antitrypsin deficiency is one of the most potentially lethal hereditary disorders. It is the leading cause of pediatric liver transplants and causes chronic obstructive pulmonary disease, with a high frequency of emphysema in adults. AAT inhibits the destructive enzymes - protease - that cause damage to the liver and to the lungs. The only known treatment for this disorder, AAT is infused on a weekly basis, after being purified from pooled human plasma and processed to reduce the potential for the transmission of infectious agents. It is crucial as a matter of public policy that individuals threatened by the unique, life-threatening diseases that plasma therapies treat not be denied timely access to the treatments they need. A patient with intracranial bleeding who is in need of a blood clotting therapy cannot wait the 24 hours that prior authorization could take to pre-approve his or her therapy.

Conclusion

Plasma therapies clearly represent the type of therapy which pharmacy and therapeutics committees should add to Medicaid PDLs. They are safe and effective, and they have no generic equivalents. Further, they have had little or no impact on the overall escalation in Medicaid drug spending. Denying immediate access to these therapies could result in greater expense to the state Medicaid program when hospitalization or skilled nursing care becomes necessary. I ask that you not subject these important life-saving therapies to prior authorization procedures.

Sincerely,

State Medicaid Directors 2008

Alabama

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Mr. Nicholas A. Toumpas, Commissioner
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New Jersey

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