

S A M P L E

Press Release

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

For Immediate Release: [Date]

Contact: [Name]

[Association chapter name]

[Phone number]

Medicaid Regulations Threaten Access to Life-Saving Therapies for Hemophilia Patients

(Annapolis, MD; DATE) Alice Smith worries that if the State Medicaid Department adopts regulations currently under consideration, her son could find it very difficult to quickly obtain the blood clotting factor so essential to his life and health.

The regulations which the Department of Health currently has under consideration are intended to control state Medicaid prescription drug costs. Under the "prior authorization" procedures proposed by the Department, doctors would have to obtain approval from the Department before prescribing any medications not on the Department's predetermined "preferred drug list" of medications. That prior approval procedure could take as long as 24 hours.

[Insert quote for named patient or parent featured in the release.]

Because Tommy Smith suffers from hemophilia, his life and health are constantly at risk. Without weekly treatment with anti-hemophilia clotting factor to prevent spontaneous bleeding, Tommy can experience bleeding into his 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 by bumps or bruises. Over time, however, this excessive bleeding can cause severe damage to internal organs and joints, leading to skeletal malformations, excruciating pain, and premature death. Such damage can be prevented only by ensuring that the proper therapies are administered in a timely manner.

During the 24-hour period which the prior authorization procedure could take, Tommy could find himself in excruciating pain from a bleeding episode. In fact the damage to Tommy's joints or organs, which could result from having to wait for his therapy, could lead to Tommy's hospitalization or require prolonged skilled nursing care, an expenditure of Medicaid moneys far greater than the cost of Tommy's clotting factor.

Many would even question whether the threat to Tommy's health and the threat of greater Medicaid expenditures is even warranted, given that the State spent only about [1 percent, or appropriate percentage for your state] of its 2006 Medicaid drug budget on blood clotting factor therapies. Compare that to the 4 percent of the State's Medicaid drug moneys spent on drugs to treat acid stomach upset. Further, while prior authorization procedures are generally designed to encourage doctors to prescribe less expensive generic alternatives, there are no generic alternatives to clotting factor therapies for Tommy's doctor to choose.

Smith and the [STATE] Hemophilia Foundation Chapter are asking the Department to exempt blood clotting factor therapies from the proposed prior authorization procedures, but so far the Department has resisted. The Department insists that all drugs should receive the same treatment under the process. It believes that, if it exempts therapies for hemophiliacs from prior authorization, other patient groups will seek a similar exemption, eventually whittling away at the effectiveness of the prior authorization procedure. Smith, however, believes that no other group would be so at risk from a denial of immediate care. She wants the Department to amend the regulations, before it formally adopts them on [DATE]. Her son's health and life are her priority. While she recognizes the need to control Medicaid costs, she believes that her son's health and life should be the Department's priority as well.

About the Association [chapter name]

The Association chapter name is the advocate for the state's hemophilia community.
[Insert brief description here.]

SAMPLE

Letter to The Editor

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

DATE

Letter to the Editor
[NEWSPAPER NAME]
[Street Address]
[City, State, Zip]

RE: Proposed Medicaid Prior Authorization

Dear Sir or Madam:

I read with great concern the report in the [DATE, Hometown Newspaper] stating that the Department of Health plans to implement a prior authorization program for Medicaid [Prior Authorization Under Consideration]. As the mother of a son who suffers from hemophilia, I worry that if the Department adopts the regulations under consideration, my son could find it very difficult to quickly obtain the blood clotting factor so essential to his life and health.

You reported that the regulations which the Department of Health currently has under consideration are intended to control state Medicaid prescription drug costs. Under the "prior authorization" procedures proposed by the Department, doctors would have to obtain approval from the Department before prescribing any medications not on the Department's predetermined "preferred drug list" of medications. That prior approval procedure could take as long as 24 hours.

Because my son has hemophilia, his life and health are constantly at risk. Without weekly treatment with anti-hemophilia clotting factor to prevent spontaneous bleeding, my son can experience bleeding into his 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 by bumps or bruises. Over time, however, this excessive bleeding can cause severe damage to internal organs and joints, leading to skeletal malformations, excruciating pain, and premature death. This damage can be prevented only by ensuring that the proper therapies are administered in a timely manner.

During the 24-hours that the state's proposed procedure could take to approve his clotting factor, my son could suffer excruciating pain from a bleeding episode. In fact the

damage to my son's joints or organs, which could result from having to wait for his clotting factor, could lead to his hospitalization or require prolonged skilled nursing care, an expenditure of Medicaid money far greater than the cost of clotting factor. An episode of intracranial bleeding could cause irreversible brain damage or death.

I question whether the threat to my son's health and the threat of greater Medicaid expenditures is even warranted, given that the State spent only about [1 percent or appropriate percentage for your state] of its 2006 Medicaid drug budget on blood clotting factor therapies. [Please see Tab 4 to determine how to calculate this percentage for your state.] Further, while prior authorization procedures are generally designed to encourage doctors to prescribe less expensive generic alternatives, there are no generic alternatives to clotting factor therapies.

The Department apparently believes that, if it exempts therapies for hemophilia from prior authorization, other patient groups will seek a similar exemption, eventually whittling away at the cost-effectiveness of the prior authorization procedure. However, no other group would be so at risk from a denial of immediate care.

My son's health and life are my priority. While I recognize the need to control Medicaid costs, I believe that my son's health and life should be the Department's priority as well.

Sincerely,

[NAME]
[Address]
[Phone]