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# LOBBYING REPORT

Lobbying Disclosure Act of 1995 (Section 5) - All Filers Are Required to Complete This Page

1. Registrant name			
Organization		National Organization for Rare Disorders, Inc. (NORD)	
2. Address <input type="checkbox"/> Check if different than previously reported			
55 Kenosia Avenue			
City	Danbury	State	CT
Zip Code	06813	Country	USA
3. Principal place of business (if different than line 2)			
City		State	
Zip Code		Country	
4a. Contact Name		b. Telephone number	c. E-mail
Prefix	Full Name		
Ms.	Diane E. Dorman	(202) 496-1296	ddorman@rare diseases.org
7. Client Name <input checked="" type="checkbox"/> Self			5. Senate ID #
National Organization for Rare Disorders, Inc. (NORD)			
			6. House ID #
			30689000

**TYPE OF REPORT** 8. Year 2005 Midyear (January 1-June 30)  OR Year End (July 1-December 3)

9. Check if this filing amends a previously filed version of this report

10. Check if this is a Termination Report  ⇨ Termination Date \_\_\_\_\_ 11. No Lobbying Activity

**INCOME OR EXPENSES - Complete Either Line 12 OR Line 13**

<p><b>12. Lobbying Firms</b></p> <p>INCOME relating to lobbying activities for this reporting period was:</p> <p>Less than \$10,000 <input type="checkbox"/></p> <p>\$10,000 or more <input type="checkbox"/> ⇨ \$ _____</p> <p>Provide a good faith estimate, rounded to the nearest \$20,000, of all lobbying related income from the client (including all payments to the registrant by any other entity for lobbying activities on behalf of the client).</p>	<p><b>13. Organizations</b></p> <p>EXPENSES relating to lobbying activities for this reporting were:</p> <p>Less than \$10,000 <input checked="" type="checkbox"/></p> <p>\$10,000 or more <input type="checkbox"/> ⇨ \$ _____</p> <p><b>14. REPORTING METHOD.</b> Check box to indicate expense accounting method. See instructions for description of option</p> <p><input checked="" type="checkbox"/> <b>Method A.</b> Reporting amounts using LDA definitions only</p> <p><input type="checkbox"/> <b>Method B.</b> Reporting amounts under section 6033(b)(8) of Internal Revenue Code</p> <p><input type="checkbox"/> <b>Method C.</b> Reporting amounts under section 162(e) of the Revenue Code</p>
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Form Con

Printed Name and Title Abbey S. Meyers, President *Abbey S. Meyers* 8/12/

0000423365




Registrant Name National Organization for Rare Disorders, Client Name National Organization for Rare Disorders

**LOBBYING ACTIVITY.** Select as many codes as necessary to reflect the general issue areas in which the registrant is engaged in lobbying on behalf of the client during the reporting period. Using a separate page for each code information as requested. Attach additional page(s) as needed.

15. General issue area code HCR - Health Issues (one per page)

16. Specific lobbying issues

Add page to continue specific issues description for this issue 

Development of medical devices for the pediatric populations  
FDA Reform

17. House(s) of Congress and Federal agencies contacted  Check if None

United States Senate  
U.S. House of Representatives  
Food and Drug Administration  
National Institutes of Health

18. Name of each individual who acted as a lobbyist in this issue area Add a page to continue adding lobbyists for this issue

First Name	Name Last Name	Suffix	Covered Official Position (if applicable)
Diane	Dorman		

19. Interest of each foreign entity in the specific issues listed on line 16 above  Check if None

Printed Name and Title Abbey S. Meyers, President

*Abbey S. Meyers* 8/12/11

10000423366



Registrant Name National Organization for Rare Disorders, Client Name National Organization for Rare Disorders

**LOBBYING ACTIVITY.** Select as many codes as necessary to reflect the general issue areas in which the registrant is engaged in lobbying on behalf of the client during the reporting period. Using a separate page for each code and provide information as requested. Attach additional page(s) as needed.

15. General issue area code MMM - Medicare/Medicaid (one per page)

16. Specific lobbying issues *Add page to continue specific issues description for this issue*

Medicare reimbursement for orphan drugs and biologics administered to patients with rare diseases

17. House(s) of Congress and Federal agencies contacted  Check if None

United States Senate  
U.S. House of Representatives  
Centers for Medicare and Medicaid Services (CMS)

18. Name of each individual who acted as a lobbyist in this issue area *Add a page to continue adding lobbyists for this issue*

Name			Covered Official Position (if applicable)
First Name	Last Name	Suffix	
Diane	Dorman		

19. Interest of each foreign entity in the specific issues listed on line 16 above  Check if None

Printed Name and Title Abbey S. Meyers, President *Abbey S. Meyers 8/12*

0000423367



Registrant Name National Organization for Rare Disorders, Client Name National Organization for Rare Disorders

**LOBBYING ACTIVITY.** Select as many codes as necessary to reflect the general issue areas in which the registrant is engaged in lobbying on behalf of the client during the reporting period. Using a separate page for each code information as requested. Attach additional page(s) as needed.

15. General issue area code BUD - Budget/Appropriations (one per page)

16. Specific lobbying issues *Add page to continue specific issues description for this issue*

Appropriations, Office of Rare Diseases, National Institutes of Health  
Appropriations, Orphan Products Research Grant Program, Food & Drug Administration

17. House(s) of Congress and Federal agencies contacted  Check if None

United States Senate  
U.S. House of Representatives  
Food and Drug Administration  
National Institutes of Health

18. Name of each individual who acted as a lobbyist in this issue area *Add a page to continue adding lobbyists for this issue*

First Name	Name Last Name	Suffix	Covered Official Position (if applicable)
Diane	Dorman		

19. Interest of each foreign entity in the specific issues listed on line 16 above  Check if None

*Add a page for a different issue area*

Printed Name and Title Abbey S. Meyers, President *Abbey S. Meyers 8/12*  
LD-2DS (REV. 4/03) Date 4

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Registrant Name National Organization for Rare Disorders, I Client Name National Organization for Rare Disorders

**Information Update Page - Complete ONLY where registration information has changed.**

20. Client new address

Address

City

State

Zip Code

Country

21. Client new principal place of business (if different than line 20)

City

State

Zip Code

Country

22. New general description of client's business or activities

**LOBBYIST UPDATE**

23. Name of each previously reported individual who is no longer expected to act as a lobbyist for the client

First Name

Last Name

Suffix

First Name

Last Name

Suffix

1

3

2

4

**ISSUE UPDATE**

24. General lobbying issues that no longer pertain

Find the code to select below.

**AFFILIATED ORGANIZATIONS**

25. Add the following affiliated organization(s)

Name	Address	Principal place of Business (city and state or country)
	Address C/S/Z	City State Country
	Address C/S/Z	City State

26. Name of each previously reported organization that is no longer affiliated with the registrant or client

1

2

3

**FOREIGN ENTITIES**

27. Add the following foreign entities

Name	Street Address City	Address State/Province Country	Principal place of business (city and state or country) City State Country	Amount of contribution for lobbying activities	Owns perce client

28. Name of each previously reported foreign entity that no longer owns, or controls, or is affiliated with the registrant, or affiliated organization

1

3

5

2

4

6

Add a page for more up

Printed Name and Title Abbey S. Meyers, President

*Abbey S. Meyers 8/10*

0000423369

