

Office of Rare Diseases (ORD) Web Site User Survey

We hope you found our Web site useful and easy to use. We would appreciate it if you could take a few minutes to complete a brief user satisfaction survey. This survey takes five minutes or less and will help us tailor our Web site to the needs of you and other users. As part of this survey, we will **NOT** ask you to disclose any personally identifiable information, and your response is completely voluntary. Your response will be confidential and used only to improve our Web site. Thank you for your time.

Note: Public reporting burden for this collection of information is estimated to average 5 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. **An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number.** Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0486). Do not return the completed form to this address.

1. Is this your first visit to the ORD Web site?

- " Yes
- " No

2. How did you first learn about the ORD Web site? (*Choose one*)

- " Family/Friend
- " Federal Government Web site
- " Search engine (Yahoo, MSN, etc.)
- " Conference/Meeting
- " Publication
- " Link from other Web site
- " Colleague
- " Other, please specify: _____

3. How would you describe yourself? (*Choose one*)

- " Patient
 - " Parent of a child with a rare disease
 - " Family/friend of a person with a rare disease
 - " Health care provider
 - " Student
 - " Researcher
 - " Other, please specify: _____
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4. What type(s) of information were you seeking on the ORD Web site? (*Select all that apply.*)

- " Information about a rare disease
 - " News/events (e.g. workshops)
 - " Research studies and clinical trials
 - " Patient support and advocacy information
 - " Genetics information
 - " Patient travel and/or lodging information
 - " Grant and/or funding information
 - " Information about ORD
 - " Other, please specify: _____
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5. Did you find the information you were seeking?

- " Yes
 - " No
- If no, what information were you unable to locate? Please write the most urgently needed information first. _____
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6. Please indicate your satisfaction with the ORD Web site, using a scale of 1 to 5, where 1 is extremely satisfied and 5 is extremely dissatisfied.

	Extremely Satisfied				Extremely Dissatisfied	Not Applicable
	1	2	3	4	5	
Web site appearance	"	"	"	"	"	"
Ease of navigation	"	"	"	"	"	"
Organization of the Web site	"	"	"	"	"	"
Usefulness of the information	"	"	"	"	"	"
Overall satisfaction with the Web site	"	"	"	"	"	"

Thank you for completing the survey.