

TRIVIA



1. Below is RAN's mission statement, fill in the blanks:

Rare Action Network serves to _____ and _____ a unified _____ of individuals and organizations with tools, training and resources to become effective _____ for rare diseases through national and state based initiatives across the United States. We stand for equitable access to timely diagnosis, treatment and care for every person impacted by a rare disease.

2. Rare Action Network's activities include:

- Awareness
- Education
- Advocacy
- All of the above

3. What year was the National Organization for Rare Disorders (NORD) founded?

- 1998
- 2003
- 1983
- 1964

4. In its inaugural year, NORD was instrumental in:

- Revising Investigational drug regulations to expand access to experimental drugs for patients with serious diseases with no alternative therapies.
- Publishing Regulations to Accelerate the Review of Drugs for life-threatening diseases.
- The passing of Orphan Drug Act, enabling FDA to promote research and marketing of drugs needed for treating rare diseases.
- All of the above

5. What is RAN's website:

- Rarediseases.org
- Rareactionnetwork.org
- Rareaction.org
- None of the above

6. What is NORD's website:

- Rarediseases.org
- NORD.org
- Rare.org
- None of the above

7. Where are NORD's office(s) located?

- Danbury, Connecticut
- Washington D.C.
- Quincy, Massachusetts
- All of the above

8. What is an advocate?

- A family member or paid helper who regularly looks after a child or a sick, elderly, or disabled person
- A person who uses their voice to raise awareness or push for a change in the way things are currently done
- A person who freely offers to take part in an enterprise or undertake a task
- People employed by a particular organization

9. What are the goals of RAN?

- Connect rare disease advocates from across the US to take action on public policy issues.
- Increase awareness of rare diseases among stakeholders at all levels of government.
- Advocate to ensure access to essential treatment for rare disease patients in all sectors of the health care system.
- All of the above

10. According to the NIH, approximately how many rare diseases are there?

- 7,000
- 5,000
- 10,000
- 8,000

11. Approximately how many Americans are affected by rare diseases?

- 5,000,000
- 80,000,000
- 30,000,000
- 50,000,000

12. What program and service does NORD offer?

- Advocacy & Education
- Patient Assistance
- Research
- All of the above

13. What is NORD's signature event?

- Rare Impact Awards
- Running for Rare
- Rare Diseases & Orphan products Breakthrough Summit
- All of the above

14. What percent of rare diseases are genetic?

- 80%
- 50%
- 95%
- 25%

15. How do you become an advocate?

- Understand the What, Who, Why and How
- Learn about current issues and legislation
- Participate in awareness campaigns and legislative meetings
- All of the above

16. Enumerated Powers are powers only held by the federal government

- True
- False

17. All state governments consist of which branches (check all that apply):

- Executive
- Legislative
- Judicial
- Health

18. What percentage of rare diseases have an FDA approved treatment?

- 20%
- 40%
- 65%
- 5%

19. Shared Powers of the state and federal government include (check all that apply):

- Tax
- Establish a judiciary
- Make and enforce laws
- Establish public schools

20. Who retains the primary responsibility for regulating health?

- Federal government
- State government

21. True or False States can pass laws that go above and beyond federal law, but cannot ignore federal law

- True
- False

22. States and the federal government can enact laws that violate your constitutional rights:

- True
- False

23. A rare disease affects less than how many of the U.S. Population?

- 500,000
- 850,000
- 200,000
- 100,000

24. What percent of rare diseases are without an FDA approved treatment or therapy?

- 55%
- 95%
- 15%
- 80%