

TRIVIA ANSWER KEY

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

Rare Action Network serves to CONNECT and EMPOWER a unified NETWORK of individuals and organizations with tools, training and resources to become effective ADVOCATES 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 it's 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. Who can sign up to become a RAN member?

- Industry representatives
- Patients & Caregivers
- Medical Professionals
- All of the above