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 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
   - NORD.org
   - Rare.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