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%

rareaction.org