Rare Diseases and Scientific Inquiry

developed under a contract from the
National Institutes of Health

Office of Rare Diseases Research

BSCS
5415 Mark Dabling Boulevard
Colorado Springs, Colorado 80918
BSCS Development Team
Mark Bloom, Co-Principal Investigator
Paul Beardsley, Co-Principal Investigator
Brooke Bourdelet-Parks, Curriculum Developer
Anne Westbrook, Curriculum Developer
Rebecca Kruse, Evaluator
Molly Stuhlsatz, Evaluator
Jon Adams, Project Assistant
Annette Plemmons, Production Manager
Stacey Luce, Production Coordinator
Chris Moraine, Production Specialist

BSCS Administrative Staff
Richard Cardullo, University of California, Riverside, California, Chair, Board of Directors
Janet Carlson, Executive Director
Pam Van Scotter, Associate Director

National Institutes of Health
Stephen Groft, Office of Rare Diseases Research
David Eckstein, Office of Rare Diseases Research
Geraldine Pollen, Office of Rare Diseases Research
Bruce Fuchs, Office of Science Education
Lisa Strauss, Office of Science Education
David Vannier, Office of Science Education
Cindy Allen, Office of Science Education

Red Hill Studios
Bob Hone, Creative Director
Sharon Hibbert, Senior Producer
Wendy Hari, Producer
Brent Tam, Associate Producer
Steve McEntee, Designer/Art Director
Charlie Brown, Senior Programmer
Dave Gonzalez, Designer/Art Director
John Hoffsis, Programmer

Advisory Committee
Sukirti Bagal, National Organization for Rare Disorders, Danbury, CT
Claireen Espinoza, Taos Day School, Taos, NM
Jennifer Hackett, The Dalton School, New York, NY
Anna Kong, Stone Academy, Chicago, IL
Henrietta List, Community Science Network, Hanover, ME
Gregory McDonald, Philadelphia College of Osteopathic Medicine, Philadelphia, PA
Philip Reilly, Independent Consultant, Concord, MA

Design Team
Steven Brügge, Eisenhower Middle School, Albuquerque, NM
Samuel Davis, Olympia High School, Orlando, FL
Timothy Garrington, University of Colorado–Denver/Children’s Hospital, Aurora, CO

Field-Test Teachers
Jean Caccioppoli, Elias Bernstein IS 7, Aberdeen, NJ
Nathaniel Franck, Our Lady of Guadalupe, Seattle, WA
Rhonda Kass, Goochland Middle School, Goochland, VA
Allan Miller, Kenai Middle School, Soldotna, AK
Anna Persson, York International, Thornton, CO
Kathryn Rice, Beaver Lake Middle School, Issaquah, WA
Mary Rodriguez, Edwards Elementary School, Chicago, IL
Katherine Smyre, West Cary Middle School, Cary, NC
Jane Suminski, Humboldt Park K–8 School, Milwaukee, WI
Mark Temons, Muncy Junior/Senior High School, Williamsport, PA
Shannon Thomas, Cocopah Middle School, Scottsdale, AZ

Reviewers
Hal Dietz, Victor A. McKusick Professor of Medicine and Genetics, Johns Hopkins University School of Medicine, Baltimore, MD
Steve Holland, Chief of the Laboratory of Clinical Infectious Diseases, National Institute of Allergy and Infectious Diseases, Bethesda, MD
Christian Kratz, Investigator, National Cancer Institute, Bethesda, MD

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Please contact the NIH Office of Science Education with questions about this supplement at supplements@science.education.nih.gov.
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Foreword

Rare Diseases and Scientific Inquiry is the most recent addition to the National Institutes of Health (NIH) Curriculum Supplement Series. This series brings the latest medical science and research discoveries from NIH into the K–12 classroom. NIH plays a vital role in the health of all Americans and seeks to foster interest in research, science, and medicine-related careers for future generations. The NIH Office of Science Education is dedicated to promoting scientific literacy and the knowledge and skills we need to secure a healthy future for all.

Rare Diseases and Scientific Inquiry gives students an opportunity to grapple with some of the most challenging and engaging medical issues that confront our society. We designed Rare Diseases and Scientific Inquiry to complement existing life science curricula and to be consistent with National Science Education Standards. Middle school science teachers, medical experts, education specialists, scientists, representatives from the NIH Office of Rare Diseases Research (ORDR), and curriculum-design experts from Biological Sciences Curriculum Study (BSCS) created the activities. The collaborative development process includes geographically dispersed field tests by teachers and students.

The curriculum supplements enable teachers to facilitate learning and stimulate student interest by applying scientific concepts to real-life scenarios. Design elements emphasize key biology concepts and analytic methods, cutting-edge science content, and built-in assessment tools. Activities promote active and collaborative learning to help students develop problem-solving strategies and critical-thinking skills.

Each of our curriculum supplements comes with a complete set of printed materials for teachers, including extensive background and resource information, detailed lesson plans, and masters for student worksheets. The Web site accompanying Rare Diseases and Scientific Inquiry has interactive materials to support the lessons. The supplements are distributed for free to educators across the United States upon request. They may be copied for classroom use and educational purposes but may not be sold.

We welcome your feedback. For a complete list of curriculum supplements and ordering information, or to submit feedback, visit http://science.education.nih.gov or write to Curriculum Supplement Series Office of Science Education National Institutes of Health 6100 Executive Blvd., Suite 3E01 Bethesda, MD 20892-7520 or supplements@science.education.nih.gov

We appreciate the valuable contributions from the talented staff at BSCS. We are also grateful to the NIH scientists, advisors, and all other participating professionals for their work and dedication. Finally, we thank the teachers and students who participated in focus groups and field tests to ensure that these supplements are both engaging and effective. I hope you find our series a valuable addition to your classroom, and I wish you a productive school year.

Bruce A. Fuchs, Ph.D.
Director
Office of Science Education
National Institutes of Health
About the National Institutes of Health

Founded in 1887, NIH is the federal focal point for health research in the United States. Today, it is one of the agencies in the Department of Health and Human Services. Its mission is science in pursuit of fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and reduce the burdens of illness and disability. NIH works toward meeting the mission by providing leadership, direction, and grant support to programs designed to improve the health of the nation through research.

NIH's education programs contribute to ensuring the continued supply of well-trained basic research and clinical investigators, as well as the myriad professionals in many allied disciplines who support the research enterprise. These efforts also help educate people about scientific results so that they can make informed decisions about their own—and the public's—health.

This curriculum supplement is one such education effort. It is a collaboration among the Office of Rare Diseases Research, the NIH Office of Science Education, and Biological Sciences Curriculum Study.

For more about NIH, visit http://www.nih.gov.

About the Office of Rare Diseases Research

The Office of Rare Diseases (ORD) was established in 1993 at the National Institutes of Health. Later, the ORD's focus on research prompted a name change to the Office of Rare Diseases Research (ORDR). The ORDR provides information on rare diseases and rare disease research; supports scientific conferences; cosponsors, with the National Human Genome Research Institute, the Genetic and Rare Diseases Information Center; and coordinates and supports research on the diagnosis and treatment of rare diseases both intramurally and extramurally. The Office also funds the Rare Diseases Clinical Research Network (RDCRN), a group of clinical research sites in the United States and several foreign countries working on about 100 different rare diseases, and is working to harmonize community efforts on patient registries and biospecimen repositories. A rare disease (also called an “orphan disease”) is a condition affecting fewer than 200,000 people in the United States (about 1 in 1,500) or one affecting more people but “for which no reasonable expectation exists that the costs of developing or distributing a drug can be recovered from the sale of the drug in the United States” (Orphan Drug Act of 1983).

For more about the ORDR, visit http://rarediseases.info.nih.gov.
About Biological Sciences Curriculum Study

Headquartered in Colorado Springs, Colorado, BSCS was founded in 1958 as a curriculum study committed to an evidence- and inquiry-based approach to science education. BSCS instructional materials and professional development services are based on current research about teaching and learning for all science classrooms, kindergarten through college.

BSCS’s materials are extensively field-tested in diverse settings across the country and evaluated for proven effectiveness. The BSCS 5E Instructional Model and inquiry are hallmarks of its materials, placing students at the center of their learning.

The BSCS mission is to transform science teaching and learning through research and development that strengthens learning environments and inspires a global community of scientifically literate citizens. BSCS is a 501(c)(3) nonprofit organization.

For more information, please visit http://www.bscs.org.