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Rare Disease Week - Cooper Library Display

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Rare Disease Week
Cooper Library Display
February 24-28, 2020

Curated by Jenessa McElfresh and Laura Stanley

Rare Disease Week Display Images



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Rare Disease Day is organised by EURORDIS-Rare Diseases Europe and 60 National alliances of patient organisations for rare diseases.



RARE DISEASE DAY.ORG

Display signs were adapted from promotional materials provided from RareDiseaseDay.org



Display Description

The Rare Disease Week book display in Cooper Library aims to highlight the history, stories, and impact of rare diseases. This display seeks to demonstrate the many types of rare diseases in the world, the foundational research texts behind disease identification and epidemiology, and the ways that communities can help support individuals living with a rare disease.

The European Organisation for Rare Diseases, a non-governmental organization, organizes a yearly Rare Disease Day that is celebrated worldwide. This book display is timed to end with Rare Disease Day on February 29, 2020. The website <https://www.rarediseaseday.org/> contains more information on this day of celebration, and the many ways individuals can get involved.

This book list is divided into two sections. The first section includes the bibliography of materials that were put on display in Cooper Library during the Rare Disease Week display from February 24-29, 2020. The second section is a bibliography of suggested additional titles for library collections to acquire to adequately represent the scope and experiences of rare diseases. Many thanks to Laura Stanley for her help creating this list of titles.

Works on Display

Baily, Mary Ann, and Thomas H Murray. *Ethics and Newborn Genetic Screening: New Technologies, New Challenges*. Baltimore: Johns Hopkins University Press, 2009.

Burch, Warner M. *100 Questions & Answers about Thyroid Disorders*. Sudbury, Mass.: Jones and Bartlett, 2009.

Gadamer, Hans-Georg. *The Enigma of Health the Art of Healing in a Scientific Age*. Cambridge, UK: Polity Press, 1996.

Giesecke, Johan. *Modern Infectious Disease Epidemiology*. Third edition. Boca Raton, FL: CRC Press, 2017.

Gilman, Sander L. *Picturing Health and Illness: Images of Identity and Difference*. Baltimore: Johns Hopkins University Press, 1995.

Grobbee, D. E., and Arno W. Hoes. *Clinical Epidemiology: Principles, Methods, and Applications for Clinical Research*. Sudbury, Mass: Jones and Bartlett Publishers, 2009.

Jurecic, Ann. *Illness as Narrative*, 2012. <http://0-site.ebrary.com.fama.us.es/lib/unisev/Doc?id=10853065>.

Kimura, Ren, ed. *Genetic Inheritance Patterns*. New York: Nova Biomedical Books, 2008.

Nussbaum, Robert L., Roderick R. McInnes, and Huntington F. Willard. *Thompson & Thompson Genetics in Medicine*. Eighth edition. Philadelphia: Elsevier, 2016.

Pollard, Tessa M. *Western Diseases an Evolutionary Perspective*. Cambridge: Cambridge University Press, 2008.

Professional Guide to Diseases. Ambler (PA): Wolters Kluwer : Lippincott Williams & Wilkins, 2008.

Sacks, Oliver. *Awakenings*. 1st ed. in the U.S. Garden City, N.Y: Doubleday, 1974.

Scott, Stuart, and Larry Platt. *Every Day I Fight*. New York: Blue Rider Press, 2015.

Smith, Moyra. *Journeys in Medicine and Research on Three Continents over 50 Years*, 2017.

Soderbergh, Steven, John Hardy, Renée Shafransky, Spalding Gray, M. J McLaughlin, Milissa Robertson, Alvin Henry, et al. *Gray's anatomy*. United States: The Criterion Collection, 2012.

Springhouse. *Nurse's Quick Check: Diseases*. Philadelphia: Wolters Kluwer Health, 2008.

<http://public.ebookcentral.proquest.com/choice/publicfullrecord.aspx?p=2032159>.

Thomson, Helen. *Unthinkable: What the World's Most Extraordinary Brains Can Teach Us about Our Own*. HarperCollins Publishers, 2018.

Weiss, Noel S. *Clinical Epidemiology: The Study of the Outcome of Illness*. 3rd ed. Monographs in Epidemiology and Biostatistics, v. 36. New York: Oxford University Press, 2006.

Zaillian, Steven, Walter F. Parkes, Lawrence Lasker, Penny Marshall, Robert De Niro, Robin Williams, John Heard, et al. *Awakenings*. Videorecording. Columbia TriStar Home Video Distributed by Image Entertainment, Inc, 1997.

Recommended Additional Titles

Crompton, Denise. *Diagnosis: Rare Disease*, 2014.

Harman, Dr. Eloise. *Rare and Interesting Cases in Pulmonary Medicine.*, 2017.

Hawkins, John T. W. *Conscience and Courage: How Visionary CEO Henri Termeer Built a Biotech Giant and Pioneered the Rare Disease Industry*, 2019.

Jones, Harrison N, and John C Rosenbek. *Dysphagia in Rare Conditions: An Encyclopedia*, 2010.
<http://public.ebookcentral.proquest.com/choice/publicfullrecord.aspx?p=1922908>.

Kane, Taylor. *Rare Like Us: From Losing My Dad to Finding Myself in a Family Plagued By Genetic Disease*.
Cork: BookBaby, 2019. <https://www.overdrive.com/search?q=C0708E41-EF9C-4A28-BBB8-7F9A3ECCCC784>.

Kelley's Journey: Facing a Rare Disease with Courage. Bloomington, Ind.: 1st Books Library, 2003.

Martín, Javier, and Francisco David Carmona. *Genetics of Rare Autoimmune Diseases*. Cham: Springer International Publishing Imprint, Springer, 2019.

National Organization for Rare Disorders. *NORD Guide to Rare Disorders*. Philadelphia: Lippincott Williams & Wilkins, 2003.

Pryde, David C, and Michael J Palmer. *Orphan Drugs and Rare Diseases*. Cambridge: Royal Society of Chemistry, 2014.

Raghavan, Derek. *Textbook of Uncommon Cancer*, 2017.

Ramirze, Wanda. Rare Diseases: Prevalence, Treatment Options and Research Insights, 2017.
<http://search.ebscohost.com/login.aspx?direct=true&scope=site&db=nlebk&db=nlabk&AN=1464649>.

Reilly, Philip. Orphan: The Quest to Save Children with Rare Genetic Disorders, 2015.

RISE (RARE DISEASE) SELLING FRAMEWORK: Rising above Traditional Skill Sets. Transformational...
Rare and Ultra-Rare Disease Therapeutics Demand Tr. S.l.: AUTHORHOUSE, 2019.

Rugary, Anne. Just like Me!: A Book about a Girl with a Rare Disease, 2018.

Sanders, Lisa. Diagnosis: Solving the Most Baffling Medical Mysteries, 2019.
<https://www.overdrive.com/search?q=C08D1921-7267-41D4-8C7E-3CCA055EA093>.

Sanfilippo, Ana, and Jimmy Lin. Rare Diseases: Diagnosis, Therapies, and Hope, 2014.

Sireau, Nicolas. Rare Diseases: Challenges and Opportunities for Social Entrepreneurs, 2017.
<http://www.myilibrary.com?id=1034600>.

Szema, Anthony M. Unusual Diseases with Common Symptoms: A Clinical Casebook, 2018.

UNDIAGNOSED AND RARE DISEASES, AN ISSUE OF CLINICS IN PERINATOLOGY. S.l.: ELSEVIER,
2020.