



## Resources on SMA, Genetic Disease, and Clinical Research Topics

This document offers information about various training resources that may be of interest for research teams working on clinical trials for spinal muscular atrophy (SMA).

Cure SMA also maintains information about trainings specifically for clinical research coordinators, available on the Cure SMA Trial Readiness Hub ([www.curesma.org/clinical-trial-readiness](http://www.curesma.org/clinical-trial-readiness)).

### Resources on SMA Diagnosis and Management

#### Cure SMA: CME Podcast Series (Free)

Cure SMA collaborated with expert clinical care stakeholders to develop a series of podcast presenting on options for management, novel therapies, and approaches for functional assessments for SMA.

<https://soundcloud.com/user-5816643>

#### The France Foundation: Urgency for Early Diagnosis and Treatment of SMA (Free)

The France Foundation collaborated with Cure SMA to present on the importance and impact of early diagnosis of SMA. The presentation is accompanied with a pre/post-test and various resources (e.g. toolkits, reference guides, etc.) related to the early detection and diagnosis of SMA.

[https://www.francefoundation.com/content/curesma/splash/story\\_html5.html](https://www.francefoundation.com/content/curesma/splash/story_html5.html)

#### NeuroSeries Live: Spinal Muscular Atrophy: Best Practices in Diagnosis and Management (Free)

Expert healthcare providers present on best clinical practices and consensus guidelines for optimized management and diagnosis of SMA.

[https://www.neuroserieslive.com/app/signup/121219\\_NSL\\_SMA\\_CME\\_Reg/formPage/0?refCode=PAR\\_CureSMA\\_SMA\\_ICYMI\\_121219](https://www.neuroserieslive.com/app/signup/121219_NSL_SMA_CME_Reg/formPage/0?refCode=PAR_CureSMA_SMA_ICYMI_121219)

#### NACCME: Navigating the Therapeutic Advances for Spinal Muscular Atrophy (Free)

NACCME hosts a webinar to discuss the clinical, economic, and psychosocial burdens of SMA, new and emerging therapies, and strategies to increase detection, diagnosis, and treatment of SMA.

<https://www.naccme.com/program/19-mcIn-209>

#### Ology Medical Education: Advances in Neurological Disorder Management (Free)

An NMD learning center provides access to various CME-accredited activities, including webcasts, patient case discussions, to promote best practices for the management of neuromuscular disorders.

<https://ologyeducation.org/neuromusculardisorders/>

#### Stanford Medicine: Spinal Muscular Atrophy: Current Advances in Treatment and Recommendations for Evaluation and Rehabilitation (Free)

The Stanford Center for Continuing Medical Education developed an online course to educate healthcare providers on the clinical perspective of SMA and how providers, outside of specialized SMA centers, can manage rehabilitation and assess SMA patients. <https://stanford.cloud-cme.com/default.aspx?P=0&EID=35514>

### Cure SMA Youtube Channel (Free)

Cure SMA's Youtube channel is home to a variety of Cure SMA webinars and other videos that may be of interest to those who want to learn more about SMA and how it affects those with the disease. The channel includes Cure SMA's SMARt Moves Video Resources, which teach viewers about the warning signs of SMA, videos from affected individuals about living with SMA – including videos on clinical meaningfulness and the impact of SMA on teens – and webinars from Cure SMA, among other videos.

<https://www.youtube.com/channel/UCECjEI49gy32nz8wWeb2AFQ>

## Resources on Genetic Diseases and Rare Diseases

### PBS: The Gene: An Intimate History (Free)

A documentary series that discusses the history of the human genome and diagnosis and treatment of genetic diseases. SMA is discussed in episode two. <https://www.kpbs.org/news/2020/apr/06/gene-intimate-history/>.

### Rare University Courses: Understanding Genetic Concepts and Drug Development (Free)

Global Genes has created two online courses that will be of interest for those new to rare disease clinical trials. The first, "Genetic Concepts for Rare Disease Patients and Families" is a series of over two dozen online lectures presented in four sections: genetic concepts, heredity and family, genetic testing, and scientific advances. The second, "Understanding Drug Development" reviews the drug development process; the roles of patients, funders, researchers, and regulators; steps in development and clinical evaluation; regulatory review; and considerations specific to rare diseases. Courses are free with a free account. <https://rareuniversity.com/courses>

## Resources on Clinical Research Topics

### ACRP Resources (Cost varies; some resources are free)

The Association of Clinical Research Professionals (ACRP) has an array of training resources for entry level, intermediate, and senior clinical research professionals. For online resources, users of their website can sort resources based on role, knowledge level, contact hours (if continuing education credits are needed), type of resource, and competency area. Many trainings are free to members, although others require payment for both members and nonmembers. ACRP also offers periodic in-person meetings and training workshops.

<https://acrpnets.org/training/>

### SOCRA ONLINE Educational Offerings for Clinical Research Education (Cost varies)

The Society of Clinical Research Associates (SOCRA) offers in-person and online training resources. Information about in-person meetings and training workshops can be found on the SOCRA website. Online courses are "intended to provide access to training and continuing education that will promote quality clinical research, protect the welfare of research participants and improve global health." The courses – which are in the form of webinars – focus on essential concepts in clinical research. The cost of the meetings and online courses varies, and some are free to members. <https://www.socra.org/conferences-and-education/online-courses/>

### Transcelerate Multimedia Library (Free)

The Transcelerate video library offers videos on a variety of important and emerging issues in clinical research, which are free to view and may be of particular interest to those who want to learn about innovations in clinical research approaches. <https://transceleratebiopharmainc.com/video/>

## Other External Resources

### Coursera Courses and Specializations (Cost varies; some courses are free)

Coursera offers a wide range of courses in clinical research, drug development, and project management topics. Individuals can search their website to learn more about specific offerings and identify courses relevant to their level of experience and professional development objectives. [www.coursera.org](http://www.coursera.org)

### EdX Courses, Programs, and Degrees (Cost varies; some courses are free)

EdX has a diverse set of courses, programs, and degrees in a large number of topics including data sciences, the life sciences, and physical sciences. EdX is both non-profit and open source. <https://www.edx.org/>

### LinkedIn Learning (Requires account; some courses are free)

LinkedIn Learning offers an ever-growing array of courses. Some courses are free, while others require a subscription. <https://www.linkedin.com/learning/>

### Cure SMA welcomes your feedback!

We would love to hear from you! Please let us know which, if any of the above resources, were helpful to you in supporting your ability to more effectively conduct / manage your trials in SMA. Please email [trialreadiness@curesma.org](mailto:trialreadiness@curesma.org).