STATEMENT OF NEED

This two-day course is intended to foster, teach healthcare providers on the clinical perspectives of spinal muscular atrophy (SMA), including the broad phenotypic spectrum of pediatric and adult patients, evidence of natural history of the disease, new updates to standards of care, clinical outcome measures/standardized assessments, and the influence of therapies both approved and in development, and second, to support healthcare providers, outside of specialized SMA centers, to manage rehabilitation in SMA. Attendees will comprehended how to translate the standards of care to clinical practice and assess SMA patients with standardized clinical measures.

LEARNING OBJECTIVES

At the conclusion of this activity, participants should be able to:
• Summarize the clinical perspectives of Spinal Muscular Atrophy including disease pathology, phenotypic spectrum, and evidence of natural history.
• Choose and organize validated rehabilitation programs based on available standards of care recommendations.
• Determine and apply appropriate clinical outcome measures based on age and function with correct administration and scoring of patient performance using these common Spinal Muscular Atrophy measures.
• The Stanford University School of Medicine is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.
• Stanford Health Care Department of Rehabilitation is an approved provider of continuing education for physicians.
• The Stanford University School of Medicine adheres to ACCME Criteria. Physicians should claim only the credit associated with the material of their participation as a faculty member.
• The California Board of Registered Nursing recognizes that Continuing Medical Education (CME) is appropriate for meeting lifelong learning educational requirements, provided the activity is designed for registered nurses.
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ACCOMPANYING MATERIALS

These common Spinal Muscular Atrophy measures.

administration and scoring of motor performance using validated standardized clinical assessments in SMA. At the end of this course, participants will have an understanding of the current advances in treatment as well as recommendations for the evaluation and rehabilitation management in SMA. Attendees will comprehended how to translate the standards of care to clinical practice and assess SMA patients with standardized clinical measures.

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SPEAKERS

Associate Professor of Neurology, University of California Los Angeles

Perry B. Shieh, MD, PhD
Occupational Therapy Services, Boston Children's Hospital

Physical Therapist, Department of Physical Therapy and University of Colorado School of Medicine

Co-Director, Neuromuscular Clinic, Children's Hospital Colorado

Haberfeld Family Endowed Chair in Pediatric Neuromuscular Disorders

Professor of Clinical Pediatrics and Neurology

Julie Parsons, MD
UT Southwestern Medical Center

Assistant Professor, School of Health Professions,

Leslie Nelson, PT, PhD, OCS
Columbia University Irving Medical Center

the Programs for Physical Therapy,

Laboratory, Children's Hospital of Philadelphia

Attending Pulmonologist and Director of the Pulmonary Function

Professor of Clinical Pediatrics

Oscar H. Mayer, MD
Clinical Specialist IV in Physical Therapy, Children's Hospital of Philadelphia

Richard S. Finkel, MD
Columbia University Irving Medical Center, The Neurological Institute

Pediatric Neurosciences

Professor of Pediatrics; Associate Chairman

Sidney Carter Professor of Neurology

Darryl C. De Vivo, MD
Associate Neurologist-in-Chief, Division of Clinical Neurology

Basil Darras, MD
Physical Therapist, Nemours Children's Hospital

Matthew Civitello, MPT
Physical Therapist, Children's Hospital Colorado

GUEST FACULTY

Carolina Tesi Rocha, MD
Pathology

Professor of Neurology and Pediatrics

John W. Day, MD, PhD
COURSE DIRECTORS

(With Genetics)

(With Neurology)

for

Connie Wolford, MSN, FNP-BC
Clinical Associate Professor, Pediatric Neurology & Neurological Science

Carolina Tesi Rocha, MD
Clinical Assistant Professor of Neurology (Affiliated); Genetic Counselor

Carly Siskind, MS, LCGC
Clinical Associate Professor, Neurology and Neurological Sciences

Jacinda Sampson, MD, PhD
Neuromuscular Fellow, Neurology and Neurological Sciences

Ava Lin, MD
Professor of Neurology and Pediatrics (Genetics) and by courtesy, Pathology

Richard Gee, PT
Physical Therapist, Division of Neuromuscular Medicine

Tina Bangtong, MPT
Physical Therapy, Division of Neuromuscular Medicine

Richard Gore, PT
Physical Therapist, Nemours Children's Hospital

Ana Luna, MD
Neuromuscular Fellow, Neurology and Neuroscientific Sciences

Jacinda Sampson, MSc, BA
Clinical Assistant Professor, Neurology and Neuroscientific Sciences

MyMy Buu, MD, FAAP
Clinical Assistant Professor, Pediatrics - Pulmonology Medicine

John M. Stoj, MD, PhD
Professor of Neurology and Pediatrics (Scleroderma and Related Diseases)

Mary E. Baer, MD, PhD
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TARGET AUDIENCE
This is an international program designed for physicians, nurses, practice nurses (NPs), physical therapists, occupational therapists, speech language pathologists, residents, fellows and medical students specializing in Neuromuscular Specialties.

LEARNING OBJECTIVES
At the conclusion of this activity, participants should be able to:
- Summarize the clinical perspectives of Spinal Muscular Atrophy including disease pathology, phenotypic spectrum, and evidence of natural history.
- Choose and organize suitable rehabilitation programs based on available standards of care recommendations.
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FRIDAY, DECEMBER 6, 2019
7:30–8:00 am  Registration + Controversial Breakfast
8:00–8:45 am  Welcome and Introductions – John Day, MD, PhD and Carolina Tesi Rocha, MD
8:45–9:45 am  SMA Pathophysiology, Diagnosis and Clinical Presentations – Sally Dunaway Young, PT, DPT and John Day, MD, PhD
9:45–10:30 am  Approval Treatment and Upcoming Therapeutic Strategies – Amy Pasternak, PT, DPT, PCS and Jacqueline Montes, PT, PhD
10:30–11:20 am  Infantile Spinal Muscular Atrophy – Carolina Tesi Rocha, MD and Richard S. Finkel, MD
11:20–12:00 pm  Pre-symptomatic Spinal Muscular Atrophy – Richard S. Finkel, MD and Connie Wolford, MSN, FNP-BC and Jacinda Sampson, MD, PhD
12:00–1:30 pm  Lunch
1:30–2:25 pm  Managing Chronic Adults with Spinal Muscle Atrophy – Connie Wolford, MSN, FNP-BC and Jacinda Sampson, MD, PhD
2:25–3:30 pm  Respiratory Management in Spinal Muscular Atrophy – Basil Darras, MD and Nora Jegoe, MD, FRACP
3:30–4:15 pm  The Patient Experience – Annette Ali, MD, and Carly Siskind, MS, LCPC
4:15–5:00 pm  Panel Discussion
Social/Reception & Cheese Event (No CME)

SUNDAY, DECEMBER 8, 2019
8:00–8:45 am  Registration + Controversial Breakfast
8:45–9:00 am  Welcome and Introductions – John Day, MD, PhD and Carolina Tesi Rocha, MD
9:00–9:45 am  SMA Pathophysiology, Diagnosis and Clinical Presentations – John Day, MD, PhD and Carolina Tesi Rocha, MD
9:45–10:15 am  SMA Clinical Presentations – Richard S. Finkel, MD and Darryl C. De Vivo, MD
10:15–10:30 am  Break
10:30–11:25 am  SMA Pathophysiology, Diagnosis and Clinical Presentations – John Day, MD, PhD and Carolina Tesi Rocha, MD
11:25–11:35 am  Panel Discussion
11:35 am–12:30 pm  SMA Pathophysiology, Diagnosis and Clinical Presentations – Oscar Mayer, MD and MyMy Buu, MD, FAAP
12:30–1:25 pm  Lunch
1:25–2:15 pm  SMA Clinical Presentations – Carolina Tesi Rocha, MD and Richard S. Finkel, MD
2:15–3:00 pm  SMA Clinical Presentations – Carolina Tesi Rocha, MD and Carolina Tesi Rocha, MD
3:00–3:30 pm  SMA Clinical Presentations – Richard S. Finkel, MD and Oscar Mayer, MD
3:30–4:15 pm  SMA Clinical Presentations – Carolina Tesi Rocha, MD and Carolina Tesi Rocha, MD
4:15–5:00 pm  Panel Discussion

PROGRAM
December 6–7, 2019 • 7:00 am – 5:15 pm

FRIDAY, DECEMBER 6, 2019
7:30–8:00 am  Registration + Controversial Breakfast
8:00–8:45 am  Welcome and Introductions – John Day, MD, PhD and Carolina Tesi Rocha, MD
8:45–9:45 am  SMA Pathophysiology, Diagnosis and Clinical Presentations – Sally Dunaway Young, PT, DPT and John Day, MD, PhD
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12:00–1:30 pm  Lunch
1:30–2:25 pm  Managing Chronic Adults with Spinal Muscle Atrophy – Connie Wolford, MSN, FNP-BC and Jacinda Sampson, MD, PhD
2:25–3:30 pm  Respiratory Management in Spinal Muscular Atrophy – Basil Darras, MD and Nora Jegoe, MD, FRACP
3:30–4:15 pm  The Patient Experience – Annette Ali, MD, and Carly Siskind, MS, LCPC
4:15–5:00 pm  Panel Discussion
Social/Reception & Cheese Event (No CME)

SATURDAY, DECEMBER 7, 2019
7:00–8:00 am  Registration + Controversial Breakfast
8:00–8:45 am  Welcome and Introductions – John Day, MD, PhD and Carolina Tesi Rocha, MD
8:45–9:15 am  SMA Pathophysiology, Diagnosis and Clinical Presentations – John Day, MD, PhD and Carolina Tesi Rocha, MD
9:15–10:00 am  Approval Treatment and Upcoming Therapeutic Strategies – Amy Pasternak, PT, DPT, PCS and Jacqueline Montes, MD, PhD
10:00–10:15 am  Break
10:15–11:05 am  SMA Clinical Presentations – Richard S. Finkel, MD and Darryl C. De Vivo, MD
11:05–11:25 am  Panel Discussion
11:25–11:35 am  Panel Discussion
11:35 am–12:30 pm  SMA Pathophysiology, Diagnosis and Clinical Presentations – Oscar Mayer, MD and MyMy Buu, MD, FAAP
12:30–1:25 pm  Lunch
1:25–2:15 pm  SMA Clinical Presentations – Carolina Tesi Rocha, MD and Carolina Tesi Rocha, MD
2:15–3:00 pm  SMA Clinical Presentations – Carolina Tesi Rocha, MD and Carolina Tesi Rocha, MD
3:00–3:30 pm  SMA Clinical Presentations – Richard S. Finkel, MD and Oscar Mayer, MD
3:30–4:15 pm  SMA Clinical Presentations – Carolina Tesi Rocha, MD and Carolina Tesi Rocha, MD
4:15–5:00 pm  Panel Discussion
5:00 pm  Adjourn

TARGET AUDIENCE
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LEARNING OBJECTIVES
At the conclusion of this activity, participants should be able to:
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ACCREDITATION
The Stanford University School of Medicine is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians. Stanford Health Care Department of Rehabilitation is an approved provider for physical therapy, occupational therapy, and speech language pathology. For courses in which the requirements are met by the respective boards.

DISCLOSURE
This course is approved for 14.5 Category 1 CME for physicians, NPs, PAs, and RNs for license renewal. Disclosure of faculty and their commercial relationships will be made prior to the activity.

FACULTY DISCLOSURE
The Stanford University School of Medicine adheres to ACGME Criteria, Standards and Policies regarding industry support of continuing medical education. Disclosure of faculty and their commercial relationships will be made prior to the activity.

Program is subject to change.
LEARNING OBJECTIVES

At the conclusion of this activity, participants should be able to:

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- Choose and organize suitable rehabilitation programs based on available standards of care recommendations.
- Determine and apply appropriate clinical outcome measures based on age and function with current administration and scoring of motor performance using these common Spinal Muscular Atrophy measures.

FRIDAY, DECEMBER 6, 2019

8:00–9:00 am
Registration • Continental Breakfast

9:00–9:15 am
Welcome and Introductions

9:15–9:30 am
SMA Pathophysiology, Diagnosis and Clinical Presentations

9:45–10:00 am
Exam – Part 1 Motor Milestones

10:15–11:00 am
Pre-symptomatic Spinal Muscular Atrophy

11:00–12:00 pm
SMA Pathophysiology, Diagnosis and Clinical Presentations

12:00–1:00 pm
Lunch

1:15–2:15 pm
Exercise Recommendations in Spinal Muscular Atrophy

2:30–3:00 pm
Pediatric and Adult SMA: The Role of Rehabilitation in Motor Nerve Function

3:15–3:30 pm
Hammersmith Functional Motor Scale - Revised Upper Limb Module (RULM)

4:15–5:00 pm
Revised Upper Limb Module (RULM)

5:15–5:30 pm
Adjourn

SCHEDULE DATES

Thursday, December 5, 2019

8:30–9:30 am
Registration • Continental Breakfast

9:30–10:15 am
Welcome and Introductions

10:15–10:30 am
SMA Pathophysiology, Diagnosis and Clinical Presentations

10:30–11:25 am
Neuromuscular Disorders (CHOP INTEND)

11:35 am–12:30 pm
SMA Pathophysiology, Diagnosis and Clinical Presentations

12:45–1:30 pm
Lunch

2:25–2:35 pm
Workshop: Literature and/or Executive Function in Individuals with SMA

2:45 –3:00 pm
Workshop: Literature and/or Executive Function in Individuals with SMA

3:00–3:30 pm
Children's Hospital of Philadelphia Infant Test of Neuromuscular Disorders (CHIPT-INTEND)

3:45–4:00 pm
Workshop: Literature and/or Executive Function in Individuals with SMA

4:15–5:00 pm
Workshop: Literature and/or Executive Function in Individuals with SMA

5:00 pm
Adjourn

Friday, December 6, 2019

7:00–8:00 am
Registration • Continental Breakfast

8:00–8:15 am
Welcome and Introductions

8:15–9:00 am
SMA Pathophysiology, Diagnosis and Clinical Presentations

9:45–10:00 am
Exam – Part 2 Motor Milestones

10:15–11:00 am
SMA Pathophysiology, Diagnosis and Clinical Presentations

11:00–12:00 pm
SMA Pathophysiology, Diagnosis and Clinical Presentations

12:00–1:00 pm
Lunch

1:15–2:15 pm
Neuromuscular Specialties

2:30–3:00 pm
Children's Hospital of Philadelphia Infant Test of Neuromuscular Disorders (CHIPT-INTEND)

3:15–3:30 pm
Hammersmith Functional Motor Scale Revised Upper Limb Module (HFMSE RULM)

4:15–5:00 pm
Children's Hospital of Philadelphia Infant Test of Neuromuscular Disorders (CHIPT-INTEND)

Saturday, December 7, 2019

7:00–8:00 am
Registration • Continental Breakfast

8:00–8:15 am
Welcome and Introductions

8:15–9:00 am
SMA Pathophysiology, Diagnosis and Clinical Presentations

9:45–10:00 am
Exam – Part 2 Motor Milestones

10:15–11:00 am
SMA Pathophysiology, Diagnosis and Clinical Presentations

11:00–12:00 pm
SMA Pathophysiology, Diagnosis and Clinical Presentations

12:00–1:00 pm
Lunch

1:15–2:15 pm
Neuromuscular Specialties

2:30–3:00 pm
Children's Hospital of Philadelphia Infant Test of Neuromuscular Disorders (CHIPT-INTEND)

3:15–3:30 pm
Hammersmith Functional Motor Scale Revised Upper Limb Module (HFMSE RULM)

4:15–5:00 pm
Hammersmith Functional Motor Scale Revised Upper Limb Module (HFMSE RULM)

5:00–5:15 pm
Adjourn

SCHEDULE

7:00–8:00 am
Registration • Continental Breakfast

8:00–8:15 am
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8:15–9:00 am
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9:45–10:00 am
Exam – Part 2 Motor Milestones

10:15–11:00 am
SMA Pathophysiology, Diagnosis and Clinical Presentations

11:00–12:00 pm
SMA Pathophysiology, Diagnosis and Clinical Presentations

12:00–1:00 pm
Lunch

1:15–2:15 pm
Neuromuscular Specialties

2:30–3:00 pm
Children's Hospital of Philadelphia Infant Test of Neuromuscular Disorders (CHIPT-INTEND)

3:15–3:30 pm
Hammersmith Functional Motor Scale Revised Upper Limb Module (HFMSE RULM)

4:15–5:00 pm
Hammersmith Functional Motor Scale Revised Upper Limb Module (HFMSE RULM)

5:00–5:15 pm
Adjourn

Program is subject to change.
Spinal Muscular Atrophy: Current Advances in Treatment and Recommendations for Evaluation and Rehabilitation

December 6 – 7, 2019
Li Ka Shing Center for Learning & Knowledge, Stanford University, Stanford, CA