

Presented by the
UCSF SCHOOL OF MEDICINE and the UCSF SCHOOL OF NURSING

21st Annual

Developmental Disabilities: Update for Health Professionals

COURSE CO-CHAIRS

Lucy S. Crain, MD, MPH, FAAP

Geraldine Collins-Bride, MS, ANP, FAAN



UCSF

March 24-25, 2022

LIVE STREAM VIRTUAL CONFERENCE

This activity is developed by a community planning and advisory committee made up of self-advocates and representatives from the following agencies: UCSF, Stanford University, The Arc San Francisco, Golden Gate Regional Center, East Bay Regional Center, State Council on Developmental Disabilities, Support for Families, WITH Foundation, San Francisco Department of Public Health, and the California Department of Developmental Services.

Photos courtesy of Support for Families, The Arc San Francisco, and Down Syndrome Connection of the Bay Area

21st Annual

Developmental Disabilities: Update for Health Professionals

LIVE STREAM CONFERENCE

This 21st annual interdisciplinary conference offers a unique update for primary care and subspecialty health care professionals and others who care for children, youth, and adults with developmental disabilities and complex health care needs. Our successful inaugural live stream conference in 2021 was well-received, reaching an audience of more than 300 registrants representing 16 states. Due to continuing concerns with the COVID 19 pandemic, we will continue the live stream format, employing a live stream webinar and user-friendly interactive virtual platforms. The live presentations will be recorded and made available for 30 days so you can review any content you might have missed. As in past pre-pandemic conferences, non-profit exhibitors will be available to provide resources to help you to deliver more informed care for patients and clients of all ages.

Most medical and health professional education programs inadequately address care for people with developmental and intellectual developmental disabilities,

The pace of new information and research provides us with exciting opportunities to transform and improve quality of care

although they represent a growing (and aging) population in the US. The pace of new information and research provides us with exciting opportunities to transform and improve the quality of care provided to these individuals. Ongoing research confirms racial disparities in access to quality health care and this conference features

presentations which include emphasis on cultural differences, political advocacy and education to promote social justice and health equity.

Our expert faculty will address topics of interest to pediatricians, family physicians, nurse clinicians, psychologists, internists and others who are involved in the health care of children and adults with developmental disabilities. This year's conference features discussions on assisted living options, medical management of cerebral palsy in children and adults, health disparities, updates in genetics, autism, and self-advocacy as well as perspectives on envisioning the future for diagnosis, prevention, and treatment of epilepsy and other conditions commonly associated with developmental disabilities. While the conference is designed and accredited for health care professionals, we welcome families and individuals with developmental disabilities to also attend.

We look forward to welcoming you to the 21st Annual Developmental Disabilities Update Conference and hope that your patients and clients with special health care needs will benefit from your participation.

Lucy S. Crain, MD, MPH, FAAP and Geraldine Collins-Bride, MS, ANP, FAAN
Conference Co-Chairs

THURSDAY, MARCH 24, 2022

7:30 am	<i>Morning Check-in</i>	
7:50	Welcome and Course Overview	Lucy S. Crain, MD, MPH, FAAP Geraldine Collins-Bride, MS, ANP, FAAN Amy J. Houtrow, MD, PhD, MPH
8:00	KEYNOTE LECTURE: Health Equity for People with Disabilities	
8:35	Q & A	
8:40	Update on the California Department of Developmental Services and Access to Care	Lauren Libero, PhD and Leinani Walter
9:10	Current Status and Progress with Federal Legislation and State Implementation of Home-based Community Services	Amanda Pyle and Mackenzie Baysinger
9:40	Q & A	
9:45	<i>Break, Exhibits</i>	
10:05	No Place Like Home – A Panel on Housing Solutions and Considerations	Moderator: Eric Zigman Panelists: Fatimah Aure, Darin Lounds, Jan Stokley
11:05	Q & A	
11:15	California's Self-Determination Program: Overview and Update	Sheraden Nicholau
11:45	Q & A	
12:00 pm	<i>Recess for Lunch</i>	
1:30	Crip Camp Panel: The Importance of Social Rec, Advocacy, and Community	Moderator: Pat Hornbecker Panelists: Melissa Crisp Cooper David Dubinsky Heather Ostrau Jane Diaz, RN
2:00	Q & A	
2:15	Orthopaedic Management of Cerebral Palsy	Kristin Livingston, MD
2:45	Rehab Management of Cerebral Palsy	Taron Davis, MD
3:15	Q & A	
3:25	<i>Break, Exhibits</i>	
3:45	Neuro-recovery Updates: Maintaining and Improving Motor Function	Adelyn Tu-Chan, DO
ANNUAL SHRIVER LECTURE & AWARD		
4:15	Introduction	
4:25	Advocacy, Inclusion and Consumer Rights	Elizabeth Grigsby
4:55	Q & A	
5:00 pm	<i>Course Adjourns</i>	

FRIDAY, MARCH 25, 2022

7:45 am	<i>Morning Check-in</i>	
7:50	Welcome and Daily Overview	Lucy S. Crain, MD, MPH, FAAP Geraldine Collins-Bride, MS, ANP, FAAN Mark Ghaly, MD, MPH
8:00	KEYNOTE LECTURE: The State of Mental Health Services for People with Developmental Disabilities	
8:35	Q & A	
8:45	Top Ten Lessons from ASAN	Julia Bascom
9:15	Q & A	
9:20	Sexual Health	Sarah Nathan, MS, RN, FNP
9:50	Q & A	
10:00	<i>Break, Exhibits</i>	
10:15	Tubes, Trachs, and Technology	Glenn Rosenbluth, MD
10:45	Q & A	
10:55	Trauma-informed Care: Use of PEARLS Screening	Karen Bohall-Ortega, MA, LMFT
11:15	TRIADS: Trauma and Resilience-informed Inquiry for Adversity, Distress, and Strengths	Anda Kuo, MD and Alicia F. Lieberman, PhD
11:35	Q & A	
11:45	<i>Recess for Lunch</i>	
THE CUTTING EDGE		
1:00 pm	Genetics 101 and Developmental Disabilities	Bryce Mendelsohn, MD, PhD
1:40	Novel Therapies for Mitochondrial Disorders	Gregory M. Enns, MD
2:20	Q & A	
2:30	Fetal Surgery for Spina Bifida: A MOMS Update	Amy J. Houtrow, MD, PhD, MPH
3:10	Q & A	
3:15	<i>Break, Exhibits</i>	
3:30	Rare or Rarely Diagnosed? Genetic Syndromes in Neurodevelopmental Disorder Patients	Joyce So, MD, PhD
4:00	Q & A	
4:05	KEYNOTE LECTURE: The Dawn of Precision Medicine in Epilepsy	Daniel H. Lowenstein, MD
4:35	Q & A	
4:40	Closing Remarks	
4:45 pm	<i>Course Adjourns</i>	

program

CHAIRS

Lucy S. Crain, MD, MPH, FAAP
Professor of Pediatrics (Emerita)
UCSF School of Medicine
Adjunct Professor of Pediatrics,
Stanford University

**Geraldine Collins Bride, MS,
ANP, FAAN**

Clinical Professor Emerita
Department of Community
Health Systems
UCSF School of Nursing

GUEST FACULTY

Fatimah Aure

Director of Field and
Capacity Building
The Kelsey

Julia Bascom

Executive Director
Autistic Self Advocacy Network

Mackenzie Baysinger

Supervisor of Community
Engagement & Quality Assurance
Golden Gate Regional Center

Karen Bohall-Ortega, MA, LMFT

Director of Special Projects
Support for Families

Melissa Crisp Cooper

Health Advocate, UCSF Office of
Developmental Primary Care

Jane Diaz, RN

Registered Nurse, Clinic by the Bay
Parent of a Person with
Developmental Disabilities

David Dubinsky

Chief Executive Officer
Pomeroy Recreation &
Rehabilitation Center

Gregory M. Enns, MD

Professor of Pediatrics
Director, Biochemical
Genetics Program
Stanford University

Mark Ghaly, MD, MPH

Secretary
California State Health and Human
Services Agency

GUEST FACULTY (CONT'D)

Elizabeth Grigsby

Consumer Rights Advocate
Golden Gate Regional Center

Pat Hornbecker

President, Board of Directors
The Arc California

Amy J. Houtrow, MD, PhD, MPH

Professor and Vice-Chair,
Department of Physical Medicine
and Rehabilitation, and of Pediatrics
Vice-Chair for Quality, Department of
Physical Medicine and Rehabilitation
University of Pittsburgh
Division Chief, Pediatric
Rehabilitation Medicine at UPMC
Children's Hospital of Pittsburgh

Lauren Libero, PhD

Autism Program Specialist
California Department of
Developmental Services

Darin Lounds

Executive Director
Housing Consortium of the East Bay

Bryce Mendelsohn, MD, PhD

Medical Geneticist
Kaiser Permanente Oakland, CA

Sheraden Nicholau

Regional Manager, Bay Area
State Council on Developmental
Disabilities

Heather Ostrau

Self-Advocate

Amanda Pyle

Director, Community Services
Golden Gate Regional Center

Jan Stokley

Executive Director
Housing Choices

Leinani Walter

Assistant Deputy Director for Service
Access and Equity
California Department of
Developmental Services

Eric Zigman

Executive Director
Golden Gate Regional Center

UCSF FACULTY

Taron Davis, MD

Assistant Professor of Orthopaedic
Surgery, and of
Pediatric Rehabilitation Medicine

Anda Kuo, MD

Professor of Pediatrics
Co-Director, CA ACES Learning and
Quality Improvement Collaborative
(CALQIC)

Alicia F. Lieberman, PhD

Irving B. Harris Endowed Chair
in Infant Mental Health
Vice Chair for Academic Affairs,
UCSF Department of Psychiatry
Director, Child Trauma Research
Program

Kristin Livingston, MD

Associate Professor of
Orthopaedic Surgery
Director of Physician Experience,
UCSF Department of Orthopaedic
Surgery

Daniel H. Lowenstein, MD

Executive Vice Chancellor and
Provost, UCSF

Robert B. and Ellinor Aird
Professor and Vice Chairman,
Department of Neurology
UCSF School of Medicine

Sarah Nathan, MS, RN, FNP

Assistant Clinical Professor
UCSF School of Nursing
Family Health Care Nursing
Department

Glenn Rosenbluth, MD

Professor of Pediatrics
Director of Quality and
Safety Programs,
UCSF Office of Graduate
Medical Education

Joyce So, MD, PhD

Associate Professor of Pediatrics
Medical Director of Adult Genetics
Division of General Internal
Medicine, Department of Medicine

Adelyn Tu-Chan, DO

Assistant Professor of Neurology
UCSF Weill Institute for
Neurosciences
Director of the Spasticity & Motor
Recovery Program, UCSF

faculty

ACCREDITATION

The University of California, San Francisco School of
Medicine (UCSF) is accredited by the Accreditation
Council for Continuing Medical Education to provide
continuing medical education for physicians.

UCSF designates this live activity for a maximum of
14.25 AMA PRA Category 1 Credits™. Physicians
should claim only the credit commensurate with the
extent of their participation in the activity.

This CME activity meets the requirements under
California Assembly Bill 1195, continuing education
and cultural and linguistic competency.

Family Physicians

Application for CME credit has been filed with the
American Academy of Family Physicians.

Determination of credit is pending.

Nursing

For the purpose of recertification, the American Nurses
Credentialing Center accepts *AMA PRA Category 1
Credit™* issued by organizations accredited by the
ACCME.

Physician Assistants

AAPA accepts category 1 credit from AOACCME,
Prescribed credit from AAFP, and *AMA PRA
Category 1 Credit™* from organizations accredited by
the ACCME.

Psychology

This educational activity is recognized by the California
Board of Psychology as meeting the continuing
education requirements toward license renewal for
California psychologists. Psychologists are responsible
for reporting their own attendance to the California
Board of Psychology. Psychologists from other states
should check with their respective licensing boards.

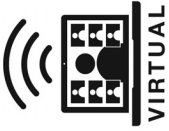
Licensed Clinical Social Workers and Marriage & Family Therapists

University of California, San Francisco School of
Medicine (UCSF) is approved by the California
Association of Marriage and Family Therapists to
sponsor continuing education for LCSWs, LMFTs,
LPCCs, and/or LEPs. UCSF maintains responsibility
for this program/course and its content.

Course meets the qualifications for **14.25** hours of
continuing education credit for LMFTs, LCSWs, LPCCs,
and/or LEPs as required by the California Board of
Behavioral Sciences.

Provider Number: 64239

No instructor or facilitator is permitted to promote or
advocate for a single modality of treatment that is
discriminatory or likely to harm clients, based upon
current accepted standards of practice. All CAMFT-
certified education must provide training on how to treat
all clients in an ethically and clinically sound manner.



REGISTER TODAY!

For early-bird registration, visit our website at cme.ucsf.edu or call (415) 476-5808. For information, cancellations, concerns, or grievances related to the course, contact the UCSF Office of Continuing Medical Education at info@ocme.ucsf.edu or call (415) 476-4251.

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Photos courtesy of Support for Families, The Arc San Francisco, and Down Syndrome Connection of the Bay Area

UCSF

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**Office of Continuing
Medical Education**

Box 0742
490 Illinois Street, Floor 8
San Francisco, CA 94143

Learning Objectives

An attendee completing this course will be able to:

1. Approach the care of patients with disabilities with an increased awareness of social and cultural differences and disparities, cognitive bias, and implications for quality access to healthcare;
2. Consult with patients and families on state and national policy issues relevant to home-based community services and access to supported living options together with important social and recreation activities for those with special needs;
3. Identify surgical and non-surgical interventions for children and adults with cerebral palsy and to know when and to whom to refer;
4. Recognize the emergence of self-advocacy and self-determination and respect their definitions and importance;
5. Describe consumer rights and inclusion considerations for people with disabilities;
6. Improve coordination with mental health services, dual diagnoses, and know when and to whom to refer for mental health concerns;
7. Apply clinical knowledge about speech and swallowing problems, indications for gastrostomy and/or feeding tubes and other practical information for patients with developmental disorders;
8. Identify and recognize genetic conditions and know when to refer patients with spina bifida and other less common disorders;
9. Describe what research holds for the future of epilepsy and other neurodevelopmental disorders;
10. Incorporate into practice elements of ACES, Trauma Informed Care, and PEARLS Screening as related to the healthcare needs of patients.

REGISTRATION • MOC22001

21st Annual Developmental Disabilities: An Update for Health Professionals

March 24-25, 2022 • LIVE STREAM CONFERENCE



Mail to : UCSF Office of CME
490 Illinois Street, Floor 8
San Francisco, CA 94143

Register online: cme.ucsf.edu
Registration Information: (415) 476-5808
Course Information: (415) 476-4251

Dr. Ms. Mr. Mrs. Mx.

LAST NAME FIRST M.I.

DEGREE SPECIALTY

ADDRESS

CITY STATE ZIP

DAYTIME PHONE FAX

EMAIL

Address Label Code Letter (see address label: example, A, B, C, D, etc.) _____

Would you like to be on our priority email list? Yes No

Please indicate if you have any special needs:

Registration Fees (Receipt/Confirmation will be mailed within two to four weeks):

- \$350** Practicing Physicians
(\$450 if postmarked after 2/15/22)
- \$250** Nurses, Other Health Professionals, and Trainees
(\$325 after 2/15/22)
- \$100** Community Members (no CE/CME credit)

Make checks payable to *UC Regents*

Please charge my credit card: Visa MasterCard American Express for \$ _____

CARD # _____ / _____
EXPIRATION DATE

NAME ON CARD (Please Print) _____ AUTHORIZED SIGNATURE _____

Please check our website for up-to-date information on the course: cme.ucsf.edu

GENERAL INFORMATION

Registration for this virtual conference will be available until 3:00 pm on **Friday March 25th**. Registrants will be given instructions to access the conference platform and the electronic course materials 1 week in advance of the conference. Recordings of the talks will be available for registrants to view on demand for 30 days post-course. All course times are based on Pacific Standard Time Zone.

How to Enroll

- Tuition:** **\$350** Practicing Physicians
(\$450 if postmarked after 2/15/22)
- \$250** Nurses, Other Health Professionals, and Trainees
(\$325 after 2/15/22)
- \$100** Community Members
(no CE/CME credit)

Payment can be made by Visa, MasterCard, AmEx or check.

Register via:

Online: cme.ucsf.edu

Mail: Complete course registration form and send with payment to:
**UCSF Office of CME • Box 0742
490 Illinois Street, Floor 8
San Francisco, CA 94143**

Phone: To register by phone or to inquire about registration status, please call UCSF's CME Registration Office at (415) 476-5808

REFUND POLICY

Cancellations received in writing before March 22nd will be refunded, less a \$75 administrative fee. No refunds will be made on cancellations received after that date.