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## The Department of Medical Genetics presents:

# Rare Disease Day 2021

February 26

Itinerary

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\*Please register for Rare Disease Day by using this link:

<https://redcap.ualberta.ca/surveys/?s=GXFXyILBFw>

### Introductions & Salutations

**11:00**

**Introduction to event: Dr. Sandra Davidge**, Distinguished University Professor, Department of Obstetrics and Gynaecology, Executive Director of the Women & Children's Health Research Institute

**Dr. Todd Alexander**, Professor, Department of Pediatrics, Associate Director of the Women & Children's Health Research Institute

**11:15**

**Salutations: Dean Brenda Hemmelgarn**, Faculty of Medicine & Dentistry

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**Moderator: Dr. Susan Christian**, Genetic Counsellor with Alberta Precision Labs

### Speaker Presentations:

**11:20**

**Dr. Todd Alexander**, Professor, Department of Pediatrics, Associate Director of the Women & Children's Health Research Institute

**Presenting: "FGF23: from discovery of this new hormone to treatment of hypophosphatemic rickets"**

15-minute virtual session

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**11:35**

**Dr. Toshifumi Yokota**, Professor, Department of Medical Genetics

**Presenting: "Emerging precision genetic medicine for muscular dystrophy and rare diseases"**

15-minute virtual session

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**11:50**

**Dr. Helly Goetz**, Pediatric Neurologist, Developmental Pediatrician  
Assistant Dean, Diversity, Faculty of Medicine and Dentistry

**Dr. Alison Eaton**, Assistant Professor, Department of Medical Genetics

**Presenting: "Precision Medicine in Rare disease: Pediatric Neuro-genetics Pilot Program"**

15-minute virtual session

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**Moderator: Dr. Narmin Kassam**, Professor and Chair, Department of Medicine, Division of General Internal Medicine

**Rare Diseases Day, Plenary Session**

**12:30-13:30**

**Dr. Oksana Suchowersky**, Professor, Department of Medicine (Neurology), Department of Medical Genetics

**Presenting:** *“Huntington Disease: A Four Decade Journey”*

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**Moderator: Dr. Saadet Andrews**, Associate Professor, Department of Medical Genetics

**Speaker Presentations cont’d**

**13:30**

**Dr. Ian MacDonald**, Professor, Department of Ophthalmology and Visual Sciences

**Presenting:** *“The what, how, where and why of ocular gene therapy”*

20-minute virtual session

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**13:50**

**Dr. Lawrence Richer**, Vice-Dean, Research (clinical), Department of Pediatrics, Division of Neurology

**Presenting:** *“Clinical trials - a paradigm shift with precision health”*

20-minute virtual session

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**14:10**

**Jason Locklin**, Director, Global Government Affairs, Access & Policy at Alexion Pharmaceuticals, Inc.

**Presenting:** *“After Health Canada approval: The Rare Disease Reimbursement Odyssey”*

20-minute virtual session

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**Closing remarks**

**14:30**

**Dr. Peter Kannu**, Chair, Associate Professor, Department of Medical Genetics