

CONGENITAL ADRENAL HYPERPLASIA

Mimi Kim, MD, MSc

Associate Professor of Clinical Pediatrics
Keck School of Medicine of USC
Co-Director, CHLA CAH Comprehensive Care Center
Los Angeles, California

Friday, July 14, 2023 – 9:00 am – 10:30 am

CAH Overview

The objectives of this talk are as follows: 1. Discuss the cause of CAH 2. Discuss the impacts on hormone productions 3. Discuss treatments and treatment goals 4. Discuss the different types of CAH

Kyriakie Sarafoglou, MD

Professor
Department of Pediatrics – Divisions of Endocrinology and Genetics and Metabolism
Department of Experimental & Clinical Pharmacology | University of Minnesota
Director, Center of Congenital Adrenal Hyperplasia and
Noah's Ark and Weiss Family CAH Research Fund and Endowment
University of Minnesota Masonic Children's Hospital
Minneapolis, Minnesota

Friday, July 14, 2023 – 10:45 am – 12:00 pm

Monitoring and Disease Control in Children with CAH

Description of Segment: Topics covered will include challenges in monitoring disease control in children with CAH; cortisol pharmacokinetic and pharmacodynamic adrenal response studies and the modeling of cortisol, 17-hydroxyprogesterone, androstenedione and testosterone to help guide toward more targeted individualized treatment; challenges in the treatment of young children with CAH; understanding the importance of both circadian and ultradian rhythms of cortisol secretion.

Mimi Kim, MD, MSc

Associate Professor of Clinical Pediatrics
Keck School of Medicine of USC
Co-Director, CHLA CAH Comprehensive Care Center
Los Angeles, California

Friday, July 14, 2023 – 1:30 pm – 2:45 pm

The Future of CAH: An Overview of Clinical Trials and Upcoming Treatments

The objectives of this talk are to summarize the clinical trial process and review current clinical trials and new treatments as they relate to CAH.

Lynn Schema, MS, LGC

Supervisor of Pediatric Genetic Counseling
Division of Genetics and Metabolism
M Health Fairview
Minneapolis, Minnesota

Friday, July 14, 2023 – 3:00 pm – 4:15 pm

Genetics and CAH

The objectives of this talk are as follows: 1. Provide an overview of basic genetic principles 2. Explain autosomal recessive inheritance 3. Review the importance of genetic testing for patients with CAH 4. Address myths and misconceptions about genetic testing 5. Highlight the role of genetic counseling for patients with CAH

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Saturday, July 15, 2023 – 9:00 am – 10:30 am

Adrenal Insufficiency – Illness Protocols and Emergency Preparedness

This session will give a deep overview of adrenal insufficiency – causes, symptoms, treatments and how to navigate illness and emergencies.

Erin Beamon

PAN/Tumor Division Consultant for The MAGIC Foundation
Mother of a child with Panhypopituitarism
&

Mimi Kim, MD, MSc

Associate Professor of Clinical Pediatrics
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Saturday, July 15, 2023 – 10:45 am – 12:00 pm

Solu-Cortef Injection Training

A brief overview of how to be prepared before, during and after an adrenal crisis including step-by-step hands on training on how to administer the Solu-Cortef injection.

GROWTH HORMONE DEFICIENCY

Aristides Maniatis, MD, FAAP

Board Certified Pediatric Endocrinologist
Rocky Mountain Pediatric Endocrinology
Associate Clinical Professor
University of Colorado Health Sciences Center
Centennial, Colorado

Friday, July 14, 2023 – 9:00 am – 10:30 am

The ABC's of GHD (Presenting Virtually)

The objectives of this talk are as follows: 1. Understand potential issues with growth including both the non-hormone and hormone causes of poor growth. 2. Understand the evaluation for Growth Hormone Deficiency. 3. Discuss the process and challenges of growth hormone therapy.

Bradley Miller, MD, PhD

Division Director, Pediatric Endocrinology
University of Minnesota Medical School
Medical Director, Discovery Clinic
M Health Fairview Masonic Children's Hospital
Minneapolis, Minnesota

Friday, July 14, 2023 – 10:45 am – 12:00 pm

Quality of Life with Treatment

During this segment we will go over the quality of life for children who are treated or denied treatment for Growth Hormone Deficiency. Consequences of non-treatment will be discussed regarding short and long-term outcomes. Finally, discussion will lead to the end of growth hormone therapy for a child and carry through treatment into adulthood.

Aristides Maniatis, MD, FAAP

Board Certified Pediatric Endocrinologist
Rocky Mountain Pediatric Endocrinology
Associate Clinical Professor
University of Colorado Health Sciences Center
Centennial, Colorado

Friday, July 14, 2023 – 1:30 pm – 2:45 pm

Long Acting Growth Hormone (Presenting Virtually)

The objectives of this talk are as follows: 1. Discuss challenges of current daily growth hormone therapy 2. Discuss principles of Long Acting Growth Hormone (LAGH) development 3. Discuss the current landscape of LAGH therapies either approved or in development

Mitchell E. Geffner, MD

Professor Emeritus of Pediatrics

Keck School of Medicine of USC

Children's Hospital Los Angeles

Ron Burkle Chair in the Center for Endocrinology, Diabetes and Metabolism

Los Angeles, California

Friday, July 14, 2023 – 3:00 pm – 4:15 pm

Puberty Management

The diagnosis and treatment of delayed puberty, as well as its short and long-term ramifications, will be discussed.

Kyle McNerney, MD

Assistant Professor, Department of Pediatrics

Division of Endocrinology & Diabetes

Washington University in St. Louis School of Medicine

St. Louis, Missouri

Saturday, July 15, 2023 – 9:00 am – 10:30 am

Evaluating and Treating Different Causes of Short Stature

In this session we will discuss a typical work-up when considering short stature. We will review examples of patients with short stature with several different diagnoses. We will specifically discuss growth hormone deficiency and growth hormone treatment, and also discuss other modalities and treatment options available for treating short stature.

Aarti S. Felder MA, LCPC, BCN

Clinical Director

TriWellness

Chicago, Illinois

Saturday, July 15, 2023 – 10:45 am – 12:00 pm

When Being Vertically Challenged Takes a Mental Health Toll

Melissa will discuss what mental health challenges come from short stature. We will discuss these concerns as it relates to elementary, middle and high school as well as transitioning to college. As parents, we will discuss how short stature can impact relationships, friendships and your child's own self-esteem and self-image.

MCCUNE ALBRIGHT SYNDROME

Michael T. Collins, MD

Senior Investigator

Skeletal Disorders and Mineral Homeostasis Section

National Institute of Dental and Craniofacial Research

National Institutes of Health

Bethesda, Maryland

Friday, July 14, 2023 – 9:00 am – 10:30 am

What you Need to Know and What to Expect in FD/MAS

Presenting on the history of McCune-Albright Syndrome and Fibrous Dysplasia and how it is believed to develop. Information on how one becomes diagnosed with MAS/FD, the different testing that needs to be done to confirm diagnosis, as well as testing that should continue to be done throughout development. Will review past and current research that is being done on MAS/FD.

Kirt E. Simmons, D.D.S., Ph.D.

Director, Craniofacial Orthodontics

Arkansas Children's Hospital

University of Arkansas Medical Sciences

Little Rock, Arkansas

Friday, July 14, 2023 – 10:45 am – 12:00 pm

Dental Components of Fibrous Dysplasia

Management and care of fibrous dysplasia within the jaw must be considered when treating patients. This segment will discuss various issues that arise and how treatments can be successfully carried out.

Alison Boyce, MD

Chief, Metabolic Bone Disorders Unit

National Institutes of Health

Bethesda, Maryland

Friday, July 14, 2023 – 1:30 pm – 2:45 pm

Endocrine Features and Anti-Resorptive Medications in FD/MAS

This presentation will cover diagnosis and management of endocrine features of FD/MAS. It will also discuss medical management of skeletal disease, including use of bisphosphonates and denosumab.

Jason Malone, DO, FAAOS

Orthopedic Surgeon
Nemours Children's Hospital
Orlando, Florida
&

Robert P. Stanton, MD, FACS

Professor, Orthopedic Surgery
University of Central Florida
Orlando, Florida
Attending Orthopedic Surgeon
Nemours Children's Hospital
Orlando, Florida

Friday, July 14, 2023 – 3:00 pm – 4:15 pm

Orthopedic Treatment of Fibrous Dysplasia: Case Presentations

Orthopedic management in MAS/FD, the most up to date ways to treat/correct FD, as well as past methods that have been found to not be as successful. Learn about rods/plates and when and when not to surgically intervene.

Dr. Stanton will be showing some cases of lower limb reconstruction and one case of scoliosis management.

Case Presentations by Dr. Stanton:

Surgical Reconstruction of Limb Deformities from Fibrous Dysplasia
Scoliosis Management in Fibrous Dysplasia

Brittany Anderson

Fibrous Dysplasia (FD) Patient

Saturday, July 15, 2023 – 9:00 am – 10:30 am

Fibrous Dysplasia: A Patient Perspective and Advocacy Movements

This segment will feature a personal journey of resilience and political advocacy from someone using their strength within to change the world for MAS/FD affected people.

Family Chat

Saturday, July 15, 2023 – 10:45 am – 12:00 pm

This is an opportunity for families to network, share stories, discuss treatments and successes that have worked for their family.

OPTIC NERVE HYPOPLASIA

Mark Borchert, MD

Board Certified Pediatric Neuro Ophthalmologist
Director, Eye Birth Defects Program and Eye Technology Program
Associate Professor of Clinical Ophthalmology and Neurology
Keck School of Medicine of USC
The Vision Center at Children's Hospital
Los Angeles, California

Friday, July 14, 2023 – 9:00 am – 10:30 am

ONH Overview

The objectives of this talk are as follows: 1. What is ONH 2. How does ONH happen 3. You have a diagnosis, now what?

Mark Borchert, MD

Board Certified Pediatric Neuro Ophthalmologist
Director, Eye Birth Defects Program and Eye Technology Program
Associate Professor of Clinical Ophthalmology and Neurology
Keck School of Medicine of USC
The Vision Center at Children's Hospital
Los Angeles, California

Friday, July 14, 2023 – 10:45 am – 12:00 pm

ONH Current Research

The objectives of this talk are as follows: 1. What does past research show? 2. What does current research show? 3. What does this mean for our children?

Ellen Lancon Connor, MD

Professor Pediatric Endocrinology and Diabetes
Co-Director, Adolescent PCOS Clinic
American Family Children's Hospital
University of Wisconsin
Madison, Wisconsin

Friday, July 14, 2023 – 1:30 pm – 2:45 pm

ONH and Endocrinology

The objectives of this talk are as follows: 1. How does the pituitary fit in with ONH? 2. How do you manage endocrine issues associated with ONH?

Mark Borchert, MD & Ellen Lancon Connor, MD

Friday, July 14, 2023 – 3:00 pm – 4:15 pm

ONH Q&A

The objectives of this talk are as follows: 1. Time to ask all your questions you have associated with ONH and endocrine issues.

Mimi Kim, MD, MSc

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PANHYPOPITUITARISM

Mitchell E. Geffner, MD

Professor Emeritus of Pediatrics

Keck School of Medicine of USC

Children's Hospital Los Angeles

Ron Burkle Chair in the Center for Endocrinology, Diabetes and Metabolism

Los Angeles, California

Friday, July 14, 2023 – 9:00 am – 10:30 am

PAN 101

The session is a broad overview of Hypopituitarism, its causes, presentations, clinical manifestations and treatments.

Mitchell E. Geffner, MD

Professor Emeritus of Pediatrics

Keck School of Medicine of USC

Children's Hospital Los Angeles

Ron Burkle Chair in the Center for Endocrinology, Diabetes and Metabolism

Los Angeles, California

Friday, July 14, 2023 – 10:45 am – 12:00 pm

What's on the Horizon

A discussion about the new research, medicine and devices, and other exciting advances in areas of interest to hypopituitarism.

Aristides Maniatis, MD, FAAP

Board Certified Pediatric Endocrinologist

Rocky Mountain Pediatric Endocrinology

Associate Clinical Professor

University of Colorado Health Sciences Center

Centennial, Colorado

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RUSSELL SILVER SYNDROME, SMALL FOR GESTATIONAL AGE & TEMPLE SYNDROME

Jennifer B. Salem, MA

MAGIC RSS/SGA

Research & Education Director

Manhattan Beach, California

Friday, July 14, 2023 – 9:00 am – 10:30 am

Building Blocks for Success in Understanding RSS/SGA/Temple: The Basics

This is a MUST SEE foundational presentation for first year attendees and those with young children given by the primary author of the guidebook. You will learn terminology and concepts necessary to understand future presentations. Unless you consider yourself an expert on RSS/SGA/Temple or have a teen, all families should plan to attend this segment PRIOR to attending additional presentations.

Dayna L. Carney, RN, CBC

Pediatric Nurse & Certified Breastfeeding Counselor

Children's Mercy Hospital

RSS Division Consultant The MAGIC Foundation

Overland Park, Kansas

Friday, July 15, 2022 – 9:00 am – 10:30 am

Letting Go: Roundtable Discussion for Parents of Teens and Young Adults

This informal moderated discussion will include several parents of older RSS children available to discuss the challenges during adolescence and young adulthood.

Yvette Q. Getch, PhD, CRC

Professor and Coordinator, Graduate Counseling Programs

University of South Alabama

Mobile, Alabama

Friday, July 14, 2023 – 9:00 am – 10:30 am

Finding Balance: The Keys to Self-Care in Adulthood

Balancing work, relationships and adult life can be challenging for all young adults. When you add in complications arising from a rare disorder, chronic health conditions and insurance challenges, one's mental health can take a toll. This presentation will focus on balancing life, coping strategies, self-care and engaging in practices to improve and maintain mental health.

Madeleine D. Harbison, MD

Assistant Professor of Pediatrics in Endocrinology

Adrenal and Steroid Disorders Group

Icahn School of Medicine at Mount Sinai

New York, New York

Friday, July 14, 2023 – 10:45 am – 12:00 pm

Unique Endocrine Issues for the RSS/SGA/Temple Child: Bone Age, Adrenarche & Insulin Resistance

As always, there are critical topics for all parents to understand fully and a discussion on bone age, adrenarche, and insulin resistance is one of them. This complex and essential presentation explains adrenarche, insulin resistance and the importance of monitoring bone age for advancement to prevent premature cessation of growth.

Bobbi McGrath, MS, CHC

Certified Regenerative Health & Detox Practitioner

Certified Health Coach & Behavioral Change Specialist

Be For You Health Coaching

Wheaton, Illinois

Friday, July 14, 2023 – 10:45 am – 12:00 pm

Taming the Stress Monster; Practical Resources You'll Actually Use

Come fill up your self-care toolbox by exploring simple strategies you can weave into your daily self-care routine that can help you manage the stress monster. You'll learn how to improve your health, mood, and overall wellbeing that doesn't cost an arm and a leg or take up mountains of time. This presentation will touch on nutrition, exercise, hormone balancing, nervous system support must-haves, and DIY detoxification strategies that move the needle on mitigating stress one small step at a time.

Suparna Jain, MD

Assistant Clinical Professor of Pediatrics

Division of Pediatric Endocrinology

UCLA-Cedars Sinai Medical Center

Private Practice Pediatric Consultants

Santa Monica, California

Friday, July 14, 2023 – 10:45 am – 12:00 pm

Medical Care How to Guide for RSS Adults

This segment will focus on the changes that come when a young adult/adult independent with their medical care. We will discuss health lifestyle choices, annual testing, doctor appointment recommendations, setting boundaries, weight management, musculoskeletal changes, how to find support and more.

Dayna L. Carney, RN, CBC

Pediatric Nurse & Certified Breastfeeding Counselor

Children's Mercy Hospital

RSS Division Consultant The MAGIC Foundation

Overland Park, Kansas

Friday, July 14, 2023 – 1:30 pm – 2:45 pm

Understanding the Role of Growth Hormone in RSS/SGA

While society may sometimes view growth hormone treatment as something they hear about in a news scandal, growth hormone is a hormone necessary for many functions, in addition to linear growth. Learn about what growth hormone is and what it does in the body as well as how growth hormone is related to health for our RSS/SGA/Temple children.

Bethany L. Cook, PsyD, HSP, MT-BC

Adjunct Professor at NLU-ISPP
Licensed Clinical Psychologist
Health Service Psychologist
Music Therapist Board Certified
Chicago, Illinois

Friday, July 14, 2023 – 1:30 pm – 2:45 pm

Parenting Road Maps for Navigating ADHD, Anxiety and Bullying

Anxiety, ADHD and bullying are complex and often intertwined issues that kids face these days. Learn how to spot early signs your child may be struggling, which doctors to seek guidance from, and techniques and skills you can apply in your family.

Professor Justin Davies, MD, FRCPCH, MRCP

Consultant Paediatric Endocrinologist Southampton
Children's Hospital Faculty of Medicine
University of Southampton
Southampton, United Kingdom

&

Karen Temple, MD

Professor of Medical Genetics, Faculty of Medicine
University of Southampton
Honorary Consultant in Clinical Genetics
University Hospital Southampton
NHS Foundation Trust
Southampton, Hampshire, United Kingdom

Friday, July 14, 2023 – 1:30 pm – 2:45 pm

Genetics and Diagnostics in Temple Syndrome

This presentation will include an overview of the current genetic findings that lead to a diagnosis of Temple Syndrome and what those may mean in terms of how each genetic finding may present differently.

Lindsay Salem-Bango, MPH

RSS Adult
Los Angeles, California

Friday, July 14, 2023 – 3:00 pm – 4:15 pm

Living with RSS/SGA; A Teen/Adult Perspective

Join Lindsay Salem-Bango, a young adult with RSS, as she moderates a discussion panel of teens and adults with RSS/SGA. Our panelists will answer pre submitted questions and share how they have handled various topics like bullying, complex medical situations, daily medications and surgical interventions. This is a wonderful opportunity to see into the future if you have a small child or simply have renewed faith in humanity as you are amazed at the resilience of this generation.

Professor Justin Davies, MD, FRCPCH, MRCP

Consultant Paediatric Endocrinologist Southampton
Children's Hospital Faculty of Medicine
University of Southampton
Southampton, United Kingdom

&

Karen Temple, MD

Professor of Medical Genetics, Faculty of Medicine
University of Southampton
Honorary Consultant in Clinical Genetics
University Hospital Southampton
NHS Foundation Trust
Southampton, Hampshire, United Kingdom

Friday, July 14, 2023 – 3:00 pm – 4:15 pm

Treatment and Management in Temple Syndrome

This is a must attend presentation for families of children with Temple Syndrome. Learn about treatment options and disorder management from the best!

Irène Netchine, MD, PhD

Professor of Physiology
Sorbonne Université Trousseau Hospital
Paris, France

Saturday, July 15, 2023 – 9:00 am – 10:30 am

Deep Dive into Study Results

Take a deep dive with us into the recent study results on topics such as adolescence, sleep disordered breathing, long term studies of adults tracked for height and insulin resistance, cyproheptadine and aromatase inhibitors.

Madeleine D. Harbison, MD

Assistant Professor of Pediatrics in Endocrinology
Adrenal and Steroid Disorders Group
Icahn School of Medicine at Mount Sinai
New York, New York

Saturday, July 15, 2023 – 9:00 am – 10:30 am

Common Gut Dysmotility Problems and Solutions

It is not uncommon for children with RSS/SGA/Temple Syndrome to have a complex relationship with eating that begins with gut dysmotility. This presentation will focus on the physical challenges that interfere and the medical interventions that are available.

Deborah JG Mackay, PhD

Professor of Medical Epigenetics

University of Southampton

Southampton, United Kingdom

Saturday, July 15, 2023 – 10:45 am – 12:00 pm

Born SGA: Molecular Testing and Diagnostic Pathway

For many parents, finding a "name" to label why their child is not growing is like being given a life preserver. They finally feel as though they are no longer floundering in a sea of uncertainty. The RSS Consensus Statement has provided a clear testing path before a clinical diagnosis of RSS should be given. Learn what diagnostic tests can tell us and the importance of pursuing testing to ensure appropriate treatment as well as avoid contraindicated treatments.

Yvette Q. Getch, PhD, CRC

Professor and Coordinator, Graduate Counseling Programs

University of South Alabama

Mobile, Alabama

Saturday, July 15, 2023 – 10:45 am – 12:00 pm

Education Accommodations; What We Need and How We Get It

For school-age children or those about to begin school, this presentation will cover the common needs and situations our children may face in school and the accommodations that may help them perform at their best and receive an equal education. We will discuss the 504 Plan and IEP and which of these may be right for your child.

GENERAL SESSIONS – SATURDAY

Linda Rio, MA, MFT

Licensed Marriage & Family Therapist

Psychological Care Institute, and Private Practice

Westlake Village, California

Saturday, July 15, 2023 – 1:00 pm – 2:00 pm

Emotional and Mental Health for Families with Pituitary Issues

Pituitary disorders certainly have an impact on the body, but the mind, behaviors, emotions, and relationships can also be deeply implicated and are often overlooked. Medical treatments focus on the body but often do not address what happens after the medical treatments. In this session parents and caregivers of children of various developmental ages and stages, from young children to adults, will learn tools, skills, challenges, and triumphs that pituitary disorders present.

MaryKathleen Heneghan, MD

Pediatric Endocrinology

Advocate Children's Hospital

Park Ridge, Illinois

Saturday, July 15, 2023 – 2:15 pm – 3:00 pm

When Should I Be Concerned about Puberty and What Are My Treatment Options

Dr. Heneghan will discuss what families should be on the lookout for, concerning early puberty, and bring to their doctor's attention if they happen too early or too late. Dr. Heneghan will also discuss treatment options to better help you decide which option is best for you and your family.

Saturday, July 15, 2023 – 3:15 pm – 4:15 pm

Learn More about the Pharmaceutical Patient Support Programs

Patient support services from growth hormone pharmaceutical companies are an integral part of treatment for families. Representatives from Ascendis, Novo Nordisk and Pfizer will each spend 15 minutes educating you about their assistance programs, which can help you through your journey. You will also have an opportunity to ask questions after the segment.