

GROWTH HORMONE DEFICIENCY

Aristides Maniatis, MD

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

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

The ABC's of GHD

The objectives of this presentation are to understand potential issues with growth as well as the non-endocrine and endocrine causes of poor growth. We will also cover the evaluation for GH deficiency and explore the process and challenges of GH therapy.

Joshua H. Yang, MD

Chief of Pediatric Endocrinology
Arnold Palmer Hospital
Orlando, Florida

Friday, July 15, 2022 – 10:15 – 11:15 am

The Future of Pediatric Growth Hormone Therapy; Where are we going from here?

By now, we have all learned the history of growth hormone, but what comes next? In this presentation, Dr. Yang will discuss the future of pediatric growth hormone therapy. With the approval of a long-acting growth hormone and other options in trials, we will learn about these treatment options.

Karen Oerter Klein, MD

Clinical Professor of Pediatrics
Rady Children's Hospital
University of California, San Diego
San Diego, California

Friday, July 15, 2022 – 11:30 am – 12:30 pm

Is it Precocious Puberty? If so, What are the Treatment Options?

Dr. Klein will cover all aspects of puberty. Focusing on what to watch for, when to expect changes, and what treatment options are available to treat if puberty should arrive earlier than expected.

Philippe Backeljauw, MD

Professor of Pediatrics
Cincinnati Center for Growth Disorders
Cincinnati Center for Pediatric and Adult Turner Syndrome Care
Cincinnati Children's Hospital Medical Center
University of Cincinnati College of Medicine
Cincinnati, Ohio

Friday, July 15, 2022 – 2:00 pm – 3:00 pm

When to Stop (or not stop) Therapy with GH for Individuals Diagnosed with GH Deficiency in Childhood? That's the Question.

Dr. Backeljauw will discuss the decision-making process for when to stop or when to continue GH therapy in patients with a diagnosis of childhood-onset GH deficiency. The audience will become familiar with the clinical manifestations associated with permanent and adult-type GH deficiency syndrome and review the practical approach for stopping or continuing GH therapy during the transition years.

Friday, July 15, 2022 – 3:15 pm – 4:15 pm

GHD Q&A

To end our day, Dr. Maniatis will sit with us in an open Q&A session. Bring all the questions that you have gathered throughout the day.

MCCUNE ALBRIGHT SYNDROME

Michael T. Collins, MD

Senior Investigator Chief

Skeletal Disorders and Mineral Homeostasis Section

National Institute of Dental and Craniofacial Research

National Institutes of Health

Bethesda, Maryland

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

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

Dr. Collins from the National Institute of Health will begin our convention by discussing McCune-Albright Syndrome and Fibrous Dysplasia. He will explain a little bit of the history behind the disease and when/how it occurs. He will teach us 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. Dr. Collins will also review the research that has been done that gave us the knowledge we have today about the disease and update us on current research.

Edward Hsiao, MD, PhD

Professor

Division of Endocrinology and Metabolism

University of California, San Francisco

San Francisco, California

Friday, July 15, 2022 – 10:15 am – 11:15 am

Fibrous Dysplasia and McCune Albright Syndrome in Adults

Dr. Hsiao will be joining us for this first time at the MAGIC convention and will be focusing his presentation on aging with MAS/FD. While the convention is typically geared towards children, there have been several requests to also have a focus on adults as we have many adult members join us. Dr. Hsiao will present on what to expect as adults with MAS/FD and is looking to have active audience participation.

Alison Boyce, MD

Associate Research Physician
Skeletal Disorders and Mineral Homeostasis Section
National Institute of Dental and Craniofacial Research
National Institutes of Health
Bethesda, Maryland

Friday, July 15, 2022 – 11:30 am – 12:30 pm

Endocrine Care and Pain in FD/MAS

Dr. Boyce, who works with Dr. Collins at the NIH will be our next presenter. She will explain how the endocrine system is involved with MAS/FD and the testing that needs to be done when suspecting MAS. She will discuss the importance of having a knowledgeable endocrinologist as part of your medical team. Dr. Boyce will also speak about testing that needs to continue to be done and at what point. She will also be presenting on pain and ways to help treat pain that patient's may experience. She will talk about medications that we have found to help with pain in MAS/FD, as well as ones that did not work as well.

Jason Malone, DO

Orthopedic Surgeon
Nemours Children's Hospital
Orlando, Florida

Friday, July 15, 2022 – 2:00 pm – 3:00 pm

Orthopedic Treatment of Fibrous Dysplasia

Dr. Malone, from Nemours Children's Hospital, will be presenting to us after lunch on orthopedic management in MAS/FD. He will teach us the most up-to-date ways to treat/correct FD, as well as touch on past methods that have been found to not be as successful. Learn about rods/plates and when and when not to surgically intervene with Dr. Malone.

Friday, July 15, 2022 – 3:15 pm – 4:15 pm

Panel Discussion with MAS/FD Patients

For the last session of the day the current plan is to have a panel discussion with a few MAS/ FD patients, as well as a parent of a child with MAS/FD. Have questions you've been wanting to ask other's similar to you? Wondering if you are the only one who has these feelings? Want to know how others with MAS/FD cope or go on with their daily life? Want to know how to explain MAS/FD to your newly diagnosed child? Now is the time to ask and get your answers from those who have lived with MAS/FD. This will be a safe, private, and open discussion. We hope people ask questions, share their story as well as openly share their feelings.

RUSSELL SILVER SYNDROME, SMALL FOR GESTATIONAL AGE and TEMPLE SYNDROME

Jennifer B. Salem, MA

RSS/SGA Director of Research & Education
The MAGIC Foundation
Manhattan Beach, California

Friday, July 15, 2022 – 9:00 am – 10:00 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 or have an RSS/SGA teen, this is the place for you.

Rachel Corcoran, MBA

RSS Adult Division Consultant
The MAGIC Foundation
Cincinnati, Ohio

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

RSS/SGA/Temple Adults Roundtable Meet & Greet

Join the new RSS adult consultant Rachel for an informal discussion about the issues that our affected adults face. Meet your fellow affected adults, share and learn from one another.

Professor Bèatrice Dubern, MD, PhD (presenting virtually)

Nutrition and Gastroenterology Department
Trousseau Hospital, Sorbonne University
Paris, France

Friday, July 15, 2022 – 10:15 am – 11:15 am

Feeding & GI Issues: Weight for Height Management

Balancing adequate calories for optimal growth while being mindful of the metabolic consequences our children face can be challenging even without the feeding frustrations common to RSS/SGA/Temple children. Dr. Dubern will discuss common feeding and gastrointestinal issues and the treatments available to help ease this difficult time.

Suparna Jain, MD (presenting virtually)

Assistant Clinical Professor of Pediatrics
Division of Pediatric Endocrinology
UCLA-Cedars Sinai Medical Center
Private Practice Pediatric Consultants
Santa Monica, California

Friday, July 15, 2022 – 10:15 am – 11:15 am

Adulthood with RSS/SGA/Temple: Stretch Marks, Autonomic Dysfunction & Self-Management

As our children become teens and young adults, they must learn to navigate and take responsibility for their own healthcare. Dr. Jain will talk about symptoms and issues that may affect them as adults, as well as provide information and support they may need as they take yet another step toward independence.

Dayna L. Carney, RN, CBC

Pediatric Registered Nurse
Children's Mercy Hospital
RSS Division Consultant
The MAGIC Foundation
Overland Park, Kansas

Friday, July 15, 2022 – 11:30 am – 12:30 pm

All About Growth Hormone for RSS/SGA/Temple

Growth hormone is an important hormone needed to help regulate growth, body structure and metabolism. Join RSS Division Consultant and RN Dayna Carney for a segment explaining why RSS/SGA/Temple children may benefit from gH therapy and its impact on long term health as well as height.

Yvette Q. Getch, PhD, CRC

Professor
Coordinator, Graduate Counseling Programs
University of South Alabama
Mobile, Alabama

Friday, July 15, 2022 – 11:30 am – 12:30 pm

The Art of Advocacy

Being the parent of a child that has growth failure and/or additional other health issues often requires us to step up and advocate for our children when they require something "extra" to equal the playing field at school and during outside activities. Dr. Getch will guide us in learning to advocate early and how to help ensure that our children learn to become their own advocates as well as how some of these decisions may impact their future.

Madeleine D. Harbison, MD (presenting virtually)

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

Friday, July 15, 2022 – 2:00 pm – 3:00 pm

Unique Endocrine Issues for the RSS/SGA/Temple Child: Bone Age, Adrenarche, Insulin Resistance & Nutrition; Does Weight Matter?

Join Dr. Harbison for an important segment covering how to and why to monitor bone age, the impact of adrenarche, understanding insulin resistance and how each of these can be impacted by weight. This a must see presentation for families of toddlers and young children.

Justin Davies, MD, FRCPCH, MRCP (presenting virtually)

Consultant Paediatric Endocrinologist
Honorary Associate Professor
University of Southampton, Southampton Children's Hospital
University Hospital Southampton
Southampton, UK

Karen Temple, MD (presenting virtually)

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

Friday, July 15, 2022 – 2:00 pm – 3:00 pm & 3:15 pm – 4:15 pm

Temple Syndrome Basics: Part 1 & 2

Dr.'s Davies and Temple will cover how Temple Syndrome is diagnosed and the most up to date treatment options. Be sure to attend the RSS/SGA Basics presentation prior to ensure understanding of foundational relevant concepts. Expect plenty of time for questions.

Friday, July 15, 2022 – 3:15 pm – 4:15 pm

RSS/SGA/Temple Q&A

This session will be the time for you to ask any questions you have about RSS/SGA/Temple

[OPTIC NERVE HYPOPLASIA/SEPTO OPTIC DYSPLASIA](#)

Mark Borchert, MD (presenting virtually)

Director of the Eye Birth Defects Program and Eye Technology Program
Associate Professor of Clinical Ophthalmology and Neurology
Children's Hospital Los Angeles
Borchert Laboratory
Los Angeles, California

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

ONH Diagnosis... Now What?

What is ONH, what are the true and fictitious clinical associations. How to navigate an ONH diagnosis.

Mark Borchert, MD (presenting virtually)

Director of the Eye Birth Defects Program and Eye Technology Program
Associate Professor of Clinical Ophthalmology and Neurology
Children's Hospital Los Angeles
Borchert Laboratory
Los Angeles, California

Friday, July 15, 2022 – 10:15 am – 11:15 am

ONH Research, Stem Cells and More

What does the latest research say about clinical risks and causes of ONH? Are stem cells the answer?

Ellen Lancon Connor, MD (presenting virtually)

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

Friday, July 15, 2022 – 11:30 am – 12:30 pm

ONH and Endocrinology

In this talk, we will learn, what is the endocrine system and how does it work? How does ONH affect the endocrine system, what labs need to be done and when?

Mark Borchert, MD & Ellen Lancon Connor, MD (presenting virtually)

Friday, July 15, 2022 – 2:00 pm – 3:00 pm

ONH Q&A

This session will be the time for you to ask any questions you have about ONH management. (endocrine, vision, medical management, emergency management and school issues)

Erin Beamon

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

Friday, July 15, 2022 – 3:15 pm – 4:15 pm

Solu-Cortef Training

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

[PANHYPOPITUITARISM](#)

Mitchell E. Geffner, MD

Professor 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 15, 2022 – 9:00 am – 10:00 am

Hypopituitarism: Out of the PAN and into the Fire

This session is a broad overview of Hypopituitarism, its causes, symptoms, and treatments.

Karen Oerter Klein, MD

Clinical Professor of Pediatrics
Rady Children's Hospital
University of California, San Diego
San Diego, California

Friday, July 15, 2022 – 10:15 am – 11:15 am

Puberty in the Panhypopituitarism Child

An overview of puberty for the Panhypopituitarism child. Delayed puberty, treatments, and the newer uses of HCG and FSH for males will be discussed.

Mitchell E. Geffner, MD

Professor 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 15, 2022 – 11:30 am – 12:30 pm

What's Oxytocin Got to Do With It?

Patients with hypopituitarism may have a deficiency of the hormone known as oxytocin, the lack of which may affect quality of life, despite apparently optimal replacement of all of the other pituitary hormones. Oxytocin plays an important role in controlling social and emotional behavior, body weight, and metabolism. Recent studies have suggested that a deficiency of oxytocin may occur in patients with hypopituitarism (and, in particular those with craniopharyngioma). Studies of the effects of treatment with oxytocin are currently underway.

Mimi Kim, MD, MSc

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

Friday, July 15, 2022 – 2:00 pm – 3:00 pm

Adrenal Insufficiency

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

Friday, July 15, 2022 – 3:15 pm – 4:15 pm

Solu-Cortef Training

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

GENERAL SESSIONS – SATURDAY

Susan Millner, M Ed, MSW, LCSW

Susan Millner Therapeutic Services
Skokie, Illinois

Saturday, July 16, 2022 – 9:00 am – 10:00 am

How to Avoid Parenting on Empty

Parenting a child with complex medical and developmental needs quickly drains energy. In this session, we will talk about ways to keep your battery charged through this parenting marathon.

Megan Donnell, MBA, SHRM-CP, PHR (presenting virtually)

SGA Division Consultant
The MAGIC Foundation
Massachusetts License - Benefits Broker
Hanover, Massachusetts

Saturday, July 16, 2022 – 10:15 am – 11:15 am

Health Insurance 101

Health insurance is complex and often frustrating. Health Insurance 101 will give you the basics - but we will also cover fully insured vs. self-funding, PBMs (Pharmacy Benefit Managers) and prescription drugs, how to evaluate and pick your plan and appeals.

Bobbi McGrath MS, CHC

Certified Regenerative Health & Detox Practitioner
Certified Health Coach & Behavioral Change Specialist
Be For You Health Coaching
Wheaton, Illinois

Saturday, July 16, 2022 – 11:30 am – 12:30 pm

Exploring the Connection Between Trauma & Chronic Health Conditions

We will explore the concept of birth trauma, early childhood neurodevelopmental gaps and the impact on the nervous system as it relates to chronic health conditions. More importantly, you will receive information, interventions and support you can explore to improve the current health state and fill in those gaps.