

Non-Profit U.S. Postage PAID Oak Park, IL Permit No. 136



Celebrating 28 years of Growth Foundation established in 1989

> July 20 - 23, 2017 The Westin Lombard Yorktown Center Lombard, Illinois

The most comprehensive educational program of the year, including social and networking opportunities for families of children, and adults, with endocrine disorders.

> Disorders to be covered: Adult Growth Hormone Deficiency (AGHD) Cushing Syndrome (CUSH) Growth Hormone Deficiency (GHD) Hypophosphatasia (HPP) McCune-Albright Syndrome/Fibrous Dysplasia (MAS/FD) Optic Nerve Hypoplasia/Septo Optic Dysplasia (ONH/SOD) Panhypopituitarism/Tumor (PAN/Tumor) Precocious Puberty (CPP) Russell-Silver Syndrome (RSS)

The MAGIC Foundation 630-836-8200 \* 800-3 MAGIC 3 \* 630-836-8181 FAX www.magicfoundation.org

Small-for-Gestational Age (SGA)



# 23<sup>rd</sup> Annual Convention



## General Convention Information

## **Convention Schedule**

#### Thursday, July 20, 2017

10:00 am - 9:00 pm	Registration desk opens
12:00 pm - 9:00 pm	Exhibits
1:00 pm - 8:00 pm	Complimentary dental screenings by Dr. Kirt Simmons (new consults)
	(Appointment required - see registration form)
6:00 pm	Teen Scavenger hunt (12 years and older)

#### Friday, July 21, 2017

7:30 am - 9:00 am	Breakfast on your own
8:30 am - 12:00 pm	Daycare open (pre-registration necessary)
8:30 am	Field trip departs to Santa's Village Azoosment Park
9:00 am - 12:00 pm	Educational segments (see centerfold)
9:30 am	Teen breakfast (12 years and older)
12:00 pm - 1:30 pm	Lunch on your own
1:15 pm - 4:30 pm	Daycare open
1:30 pm - 4:15 pm	Educational segments (see centerfold)
4:15 pm	Field trip returns
4:30 pm - 5:30 pm	Men's Mix & Mingle
6:00 pm	Prince, Princess & Pirate Party
	Do mostive and use your imperination to duose unl

- Be creative and use your imagination to dress up!
- Prizes will be awarded for the most unique costumes
- Entertainment provided
- Buffet dinner will be served

#### Saturday, July 22, 2017

7:30 am - 9:00 am	Breakfast on your own
8:30 am - 12:00 pm	Daycare open
9:00 am - 12:00 pm	Educational segments
12:00 pm - 1:30 pm	Lunch on your own
1:30 pm - 4:30 pm	Educational segments
1:30 pm - 4:30 pm	Daycare open
4:30 pm - 5:30 pm	Ladies' Mix & Mingle
6:00 pm	Pizza and Networking Party

## Sunday, July 23, 2017

10:00 am - 12:00 pm

Farewells from a MAGICal weekend by registration booth

## www.magicfoundation.org

#### <u>Dates</u>

Thursday, July 20, 2017 - Sunday, July 23, 2017

#### Location

The Westin Lombard Yorktown Center 70 Yorktown Center, Lombard, IL 60148 (630) 719-8000

#### **Convention Registration Fee**

\$195 - This fee includes immediate family only Additional adults are \$25 each (grandparents, aunts/uncles, friends, etc.)

# Registration fees and forms are due by June 27, 2017. Any registrations received after this time will be charged a late fee of \$25. There will be no refunds after June 27th.

#### Payment Methods

Payment of registration fees by check is preferred. This avoids additional costs to MAGIC. Make checks payable to: MAGIC Foundation. To pay by credit card, please include information on registration form.

#### <u>Daycare</u>

American ChildCare Services will be providing professional daycare at MAGIC's convention. They will have rooms setup for the following ages: 12 weeks to 2 years, 3-6 year olds, and 7-16 year olds. Age appropriate activities will be provided in each room, as well as entertainment. The cost is \$55 per child, per day. Pre-registration is necessary and can be done via their website, <u>www.americanchildcare.com/magic</u> or by calling 312-644-7300 to obtain registration forms. American ChildCare Services will also be available on Thursday during exhibit hours for pre-registration.

#### Hotel Room Rates and Reservations

#### \$ 104 per night **(\$115.44 with tax)**

All rooms have refrigerators!! The deadline to book your room is June 27, 2017. A limited number of roll-aways and cribs are available at no cost so if you need one be sure to request one when making your hotel reservation. To make hotel reservations call the Westin at 888-627-9031, and mention The MAGIC Foundation guest room block, or book online at:

https://www.starwoodmeeting.com/StarGroupsWeb/res?id=1702038720&key=1B67B2B1

#### Airport Transportation

The airport of choice is O'Hare (ORD) which is located closer to the hotel and has shuttle service to/from the Westin Hotel. Midway (MDW) is in Chicago also but a distance from the hotel. Please read "hotel transportation" below before booking a flight.

#### Hotel Transportation

Free shuttle service is provided by Windy City Limo's to the Westin Lombard from O'Hare Airport only! <u>The shuttle schedule is as follows:</u> O'Hare Airport to the Westin - **Thursday** - 11 am, 1 pm, 3 pm, 5 pm and 7 pm Westin to O'Hare Airport - **Sunday** - Pickups at 9 am, 11 am, 1 pm, 3 pm and 5 pm Shuttle buses will have a MAGIC sign in the window and will pick up at the following O'Hare locations: **Terminal 1, Door 1G \* Terminal 2, Door 2E \* Terminal 3, Door 3G \* Int'l Terminal, Door 5E** Pick up will be in the middle aisle when you exit the doors from baggage claim.

If you are unable to find the shuttle, you can contact Windy City at 866-949-4639. You may choose to arrive at Midway Airport but there is no free transportation available and a taxi will cost approximately \$40.

**NOTE:** If you use a power wheelchair/scooter or other device which cannot be folded and need wheelchair accessible transportation, you can contact Special Needs Chicago at (630) 668-9999 or visit their website to make arrangements online, <u>www.specialneedschicago.org</u>

## **Program Details**

#### Registration/Exhibits (Thursday)

Convention packets will be distributed when you register with MAGIC at the Westin. Exhibitors are representatives from companies that provide medical products and services often used by the families attending the convention. The representatives are available to answer questions and distribute helpful literature. In addition, they sponsor special fun activities for children during this time. This is a great time to meet other families and socialize in an informal atmosphere. Refreshments will be served.

#### Dental Screening (Thursday)

Dr. Kirt Simmons will be available from 1:00 - 8:00 pm for complimentary dental consultations. Appointments are mandatory and will last approximately 10 minutes. Appointments are made on a first come, first serve basis and are open to new consults only. You will be notified by email regarding your appointment status. See registration form to make an appointment.

#### Teen Scavenger Hunt (Thursday)

This is a great opportunity for the older kids to meet, hang out and have a scavenger hunt! Everyone 12 years and older is welcome. Be sure to sign up on the registration form. Meet in front of the MAGIC registration desk at 6pm on Thursday.

#### Field Trip (Friday, during educational segments)

Adult-chaperoned field trip to Santa's Village Azoosment Park. The cost of \$40 per child includes admission, transportation and lunch (pizza and a drink). Children must be 6 years or older, unless accompanied by an adult family member. To learn more about Santa's Village, visit their website at www.santasvillagedundee.com.

#### Teen Breakfast (Friday)

If your teen isn't attending the field trip, let them "sleep in" then join other teens for a casual, complimentary breakfast. Anyone 12 and older is welcome. Parent volunteers will be supplying breakfast.

#### Daycare (Friday & Saturday)

The \$55 cost per child/per day covers professional daycare (at the hotel) during the educational segments Friday and Saturday. Children must be picked up at daycare during lunch breaks both days. Daycare is closed during lunch. If you have children going into daycare, you must pre-register them with American ChildCare Services. Pre-registration can be done via their website, www.americanchildcare.com/magic, or by calling 312-644-7300 to obtain registration forms. Pre-registration will also be available on Thursday during exhibit hours.

#### Men's Mix and Mingle (Friday)

MAGIC realizes there is also a need for the men to get together, so we have planned an informal gathering. Light snacks and beverages (no alcohol) will be provided. The event will be held in one of the meeting rooms at the hotel. No children allowed!

#### Prince, Princess & Pirate Party (Friday)

Have fun, be creative and use your imagination to dress up! Prizes will be awarded for best costumes! Buffet dinner will be served and entertainment will be provided.

#### Ladies' Mix and Mingle (Saturday)

Join other ladies for a little relaxation time. Light snacks and beverages (no alcohol) will be provided! The event will be held in one of the meeting rooms at the hotel. No children allowed!

#### Family Pizza and Networking Party (Saturday)

Each division will have a pizza and networking party on Saturday evening. Be sure to attend and gather with those who have the same diagnosis as someone in your family. This is a family event and children are welcome.

#### DISCLAIMER

Free screenings conducted by medical professionals acting in a volunteer capacity during a MAGIC Foundation sponsored activity or event of any kind are intended solely for the purpose of educating attendees and identifying the symptoms of growth disorders and or associated complications of growth disorders. The free screenings are limited and are not intended to constitute a complete medical exam or provide a complete or final diagnosis. The MAGIC Foundation, through and on behalf of its officers, directors, agents, volunteers and representatives, is not responsible for the material presented, parental comments, nor screening opinions during any Foundation sponsored event. Always consult your personal medical specialists prior to making medical decisions. Educational programs are not a replacement for the relationship you have with your healthcare provider. Any information provided is the opinion of the medical presenter and should not be substituted for regular consultation with your healthcare provider. If you have any concerns about your health, please contact your healthcare provider's office. Information provided during a screening is not being used to make diagnoses, administer treatment, prescribe medications, or order tests. The information contained is provided as an educational service, which can assist you in your personal research on a specific disease.

#### Deanna Adkins, M.D.

Assistant Professor of Pediatrics Fellowship Program Director Division of Pediatric Endocrinology Duke Children's Health & Hospitals Durham, North Carolina

#### Susan Beauregard, RN BSN

Endocrine Stim Nurse Phoenix Children's Hospital Phoenix, Arizona

#### Danielle Binns, CNP, BA

Certified Nutritionist & Picky Eating Expert Health & Happiness Coach for Moms Co-Founder of Paediatric Nutrition & Feeding Workshop Mom of RSS daughter Toronto, Ontario Canada

#### Mark S. Borchert, M.D.

Director Eye Birth Defects Institute Director, Eye Technology Institute The Vision Center Children's Hospital Los Angeles Associate Professor of Clinical Ophthalmology & Neurology Keck School of Medicine. University of Southern California Los Angeles, California

#### Alison M. Boyce, M.D. Pediatric Endocrinologist

National Institutes of Health Bethesda, Maryland

#### Andrea B. Burke, DMD, M.D.

Assistant Professor. Oral & Maxillofacial Surgery University of Washington School of Dentistry Seattle, Washington

#### Mark L. Cannon D.D.S., M.S.

Northwestern University Feinberg School of Medicine Division of Dentistry Ann & Robert Lurie Children's Hosp. Chicago, Illinois

Wendy S. Coleman, M.D. Behavioral Pediatrician UW Health Pediatrics Madison, Wisconsin

#### Michael T. Collins, M.D.

Chief, Section on Skeletal Disorders & Mineral Homeostasis Director, Career Development & Research Training NIH Inter-institute Endocrine Training Program National Institutes of Health Bethesda, Maryland

#### Ellen Lancon Connor, M.D.

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

#### Kathryn McCrystal Dahir, M.D.

Associate Professor of Medicine Associate Fellowship Director Vanderbilt University Medical Center Endocrinology and Diabetes Nashville, Tennessee

#### Béatrice Dubern M.D., Ph.D.

Associate Professor Trousseau Children's Hospital Nutrition & Gastroenterology Dept. Pierre et Marie Curie School of Med. Paris, France

#### Mitchell E. Geffner, M.D.

Professor of Pediatrics Keck School of Medicine of USC Chief, Center for Endocrinology, Diabetes & Metabolism Children's Hospital Los Angeles Ron Burkle Chair in the Center for Endocrinology, Diabetes & Metabolism Co-Director, CAH Center of Excellence at CHLA Los Angeles, California

#### Yvette Q. Getch, Ph.D., CRC

Associate Professor, WKU & Student Development Coordinator WKU Learn and Earn Western Kentucky University Bowling Green, Kentucky

#### Kyle Gillett, Ph.D., LMFT

Executive Director, Therapist Equinox RTC **Owner**, Solstice Programs Hendersonville, North Carolina

Dan Hadley, M.S., LMFT Clinical Director, Therapist Equinox RTC Hendersonville, North Carolina

#### Madeleine D. Harbison, M.D.

Assistant Professor of Pediatrics Adrenal and Steroid Disorders Pediatric Endocrinology Mt. Sinai School of Medicine of NY University New York, New York



# Faculty

#### Lisa Marie Hodges

Research Fellow Health Psychologist in Training University of the West of England, UK. University Hospital Southampton NHS Foundation Trust, UK

#### Omar D. Hudson, M.D.

Division of Pediatric Endocrinology-Health First Medical Group Melbourne, Florida Clinical Faculty, University of Central Florida College of Medicine Orlando, Florida

#### Hannah Jordan

Junior Co-Founder Still Life Cycling Sponsored Athlete Colnago, HED Wheels, Oakley, Generation Ucan, Cocoa Elite, D1 Tulsa & Pickle Juice Tulsa, Oklahoma

#### Laurence Katznelson, M.D.

Associate Dean of Graduate Medical Education Professor of Neurosurgery & Medicine Medical Director, Pituitary Center, Stanford School of Medicine Stanford, California

#### Mimi Kim, M.D., MSc

Associate Prof. of Clinical Pediatrics Keck School of Medicine of USC Co-Director. CAH Comprehensive Care Clinic Los Angeles, California

#### Dorit Koren, M.D., MTR

Attending Physician Assistant Director. Pediatric Diabetes Center Pediatric Endocrine Unit Massachusetts General Hospital Boston, Massachusetts

#### Crystal Lee, PTA

Certification in Aquatic Therapy San Joaquin Valley Rehab Fresno, California

#### John Madderra

Bachelor's and Master's Degree of Science in Mechanical Engineering University of Alabama Advocate for Children with AI Helena, Alabama

#### Dori Middleman, M.D.

**Board Certified Child** & Adult Psychotherapy The PA Gestalt Center for Psychotherapy and Training The Health Annex of the Family Practice and Counseling Network The Mary Howard Health Center Bala Cynwyd, Pennsylvania

#### Bradley S. Miller, M.D., Ph.D.

Associate Professor Pediatric Endocrinology University of Minnesota Masonic Children's Hospital Minneapolis, Minnesota

#### Irène Netchine, M.D., Ph.D.

Associate Professor Trousseau Children's Hospital Pierre et Marie Curie School of Medicine Paris, France

#### John Rinehart, M.D., JD, Ph.D.

Senior Educator Pritzker School of Medicine University of Chicago Chicago, Illinois

#### Lindsay Salem

**RSS** Young Adult Manhattan Beach, California

#### Jennifer B. Salem, M.A.

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

#### Jill Simmons, M.D.

Associate Professor of Pediatrics, Ian Burr Division of Pediatric Endocrinology and Diabetes Director, Pediatric Program for Metabolic Bone Disease Vanderbilt University Medical Center Nashville, Tennessee

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

Director, Craniofacial Orthodontics Arkansas Children's Hospital Little Rock, Arkansas

#### Robert P. Stanton, M.D., F.A.C.S

Nemours Children's Hospital Department of Orthopedics Orlando, Florida

#### Jonathan Weber, M.D.

Pediatric Endocrinology Fellow Division of Endocrinology, Diabetes & Metabolism Children's Hospital Los Angeles Los Angeles, California

#### Brinkley Werley, MSW, LCSWA, LCASA

Director, Therapist Journey Home East Asheville, North Carolina

#### Joanne Zucker, M.S. Ed

Adult with ONH/SOD Teacher for the Blind & Visually Impaired Clinton County, New York

## Segment Descriptions

#### Adult Growth Hormone Deficiency

Consultant ~ Randy Fishburn

Friday morning will begin with Dr. Kim discussing various medication options dealing with AI for both Cushing's patients and those who deal with AI due to Panhypopituitarism. She will include the new longer acting hydrocortisone and the adrenal pump. Next, Dr. Gillett and therapists, Dan & Brinkley, will help us learn to live with our chronic illnesses. When the whole world (including your own body) is out to get you, it's easy to build up walls and push everyone away. Come explore with us how to create the peace, hope, happiness and healing necessary to let supportive connections back in. After lunch, Dr. Weber will cover Pituitary 101... the basics, followed by Dr. Katznelson who will cover Pituitary 201 that will go into more detail how our bodies use the different hormones & how it can affect the disorders of AGHD, PAN & Cushing's.

As we separate from the Cushies for a couple of segments, our AGHD/PAN group will have a speaker on the topic of fertility who will cover issues with both males & females. We will leave a full 1/2 hour at the end for questions, as I am sure there will be many. Then Dr. Miller will cover what is happening in the world of long acting growth hormone. While these products are not yet available, he will cover the newest revelations on the future treatment options & update us on the status of the studies. Then we have the opportunity to hear Dr. Getch speak to us on Defeating Depression. This is a topic I am sure we can all get behind. Then we are going to do a full turn around with our last speaker, Dr. Gillett and therapists, Dan & Brinkley, sharing a motivational session with us... one to leave us with high spirits & hope for our future. This session is open to all attending the convention (including pediatric group too).

## **Cushing Syndrome**

Consultant ~ Jackie Edgar

Friday morning will begin with Dr. Kim discussing various medication options dealing with AI for both Cushing's patients and those who deal with AI due to Panhypopituitarism. She will include the new longer acting hydrocortisone and the adrenal pump. Next, Dr. Gillett and therapists, Dan & Brinkley, will help us learn to live with our chronic illnesses. When the whole world (including your own body) is out to get you, it's easy to build up walls and push everyone away. Come explore with us how to create the peace, hope, happiness and healing necessary to let supportive connections back in. After lunch, Dr. Weber will cover Pituitary 101... the basics, followed by Dr. Katznelson who will cover Pituitary 201 that will go more into detail how our bodies use the different hormones & how it can affect the disorders of AGHD, PAN & Cushing's.

On Saturday, we break our sessions & our Cushies will begin our day with Dr. Katznelson who will discuss our journey... from early symptoms to diagnosis to surgical or medical treatment. He will discuss the confusing journey a Cushing's patient can face, touching on familial/genetic causes and cyclical disease and the role the pituitary and adrenal glands play. Next, Dr. Middleman, who is a Cushing's Disease survivor, joins us to share her journey through diagnosis and recovery. She is the author of "How To Have Fun With A Brain Tumor" and "Psychiatric Issues with Cushing's Disease". She has counseled many Cushing's patients and remains active in the Cushing's community. Then we have the opportunity to hear Dr. Getch speak to us on Defeating Depression. This is a topic I am sure we can all get behind. Then we are going to do a full turn around with our last speaker, Dr. Gillett and therapists, Dan & Brinkley, sharing a motivational session with us... one to leave us with high spirits & hope for our future. This session is open to all attending the convention (including pediatric group too).

#### **Growth Hormone Deficiency**

Consultant ~ Teresa Tucker

Our GHD day will start with 30 minutes of introductions and then Dr. Hudson will speak to us about how the body uses growth hormone for more than just growth. Our next speaker Dr. Adkins will address puberty... when it is normal, what to do if it comes early, & what the treatment options are to delay puberty. Shots can be intimidating for some and living with a chronic illness can leave you feeling like a pin cushion. Join Dr. Gillett and therapists, Dan and Brinkley, as they address the challenges of injection anxiety, and explore ideas on how to help our children cope with years of daily injections. Our last Friday speaker is Susan Beauregard, an RN from Phoenix Children's Hospital who will present the results of a study regarding use of Zofran in the Stim test. Our Saturday will begin with Dr. Miller discussing what happens at the end of treatment... is it really over? What do the endocrinologists recommend after your child gets their last growth hormone injection? And we will conclude again this year with our Q&A session. A time to casually ask all those questions that are now crowding your mind.

SATURDAY	ALL DIVISIONS WELCOME						
1:30 PM - 2:45 PM	<u>Breakout</u> Parents O Affected Kid	Family Cope <u>sessions for:</u> NLY - <b>Hadley</b> s ONLY - <b>Gillett</b> NLY - <b>Werley</b>	Dep	feating pression <b>Getch</b>			
3:00 PM - 4:15 PM	Transition Empowerment for Parents ONLY <b>J. Salem</b>	Transition Empowerment for Affected Kids ONLY <b>L. Salem</b>	Psych for Siblings <b>Getch</b>	Discovering Joy in Family Life! <b>Gillett,</b> <b>Hadley &amp; Werley</b>			

## Saturday Segment Descriptions

#### Helping a Family Cope

Chronic illnesses impact every member of the family. In this session, we'll be breaking into groups of Parents ONLY, Siblings ONLY and Affected Kids ONLY to explore the different ways that each family member is affected. Be ready to share feelings, connect, play, and learn what you can personally do to take care of yourself while contributing to the emotional health of your family.

#### Defeating Depression

Life with a chronic illness can sometimes be difficult. Join Dr. Yvette Getch to learn some coping techniques for dealing with depression in every day life. Come prepared to share your feelings and learn how to take care of you! This session is for affected adults ONLY.

#### Transition Empowerment

Parents: Join us for a session on learning how you can help guide your older teen or young adult towards making medical decisions for themselves. Learn the do's and don'ts from a mom who has been through this process. While this session is presented by Jennifer Salem, parent of an RSS young adult, she will be addressing all of our disorders. We will also have a panel of parents, one from each division, for a 15 minute Q&A at the end of the presentation.

Affected Individuals: Now is the time for you to start taking over control of your medical care. Even if you are not a young adult yet, it is never too soon to learn how to advocate for yourself. Lindsay Salem is a college student who has learned the difficulties in navigating the medical world on her own. She will share tips that have worked for her and other adults.

#### Psych for Siblings

It is often not easy having a sibling with a chronic illness. Maybe you often feel like your brother or sister gets more attention than you because they need frequent medical care! Come share your thoughts with other siblings and listen to some advice Dr. Yvette Getch will share.

#### Discovering Joy in Family Life!

Let's all face it - life is far from perfect... So why's everyone always running around trying to make it look like theirs is? Medical conditions really STINK, but with an open mind, and sometimes even a little irreverence, we can still discover joy in family life! Join us in the final session of the conference to explore how to recognize joy in the little things and find the FUN in dysFUNctional.

## Saturday Segments

## Segment Descriptions (continued)

## Panhypopituitarism/Tumor

Consultant ~ Erin Beamon

Dr. Geffner will begin our day presenting an easy to understand overview of the development and anatomy of the pituitary gland, it's normal function, the causes and clinical presentation of panhypoptuitarism, and the diagnosis and treatment of the hormone deficiencies associated with the diagnosis. Next, Dr. Koren will be discussing sleep issues associated with panhypopituitarism and what has been discovered in current research. After lunch, John Madderra will be presenting how to work with your state and local city/county emergency medical personnel to set up Adrenal Insufficiency protocols for your county or town. Most areas do not allow EMS personnel to inject Solu-Cortef and they do not even carry the medication on their vehicles. This session will discuss how to connect and create good working relationships in the hopes of creating and enacting protocols that allow EMS workers to treat someone who has Adrenal Insufficiency. Our last session, Dr. Coleman will be discussing how our kids face more doctor appointments every year than many of their peers and how managing their care can be emotionally draining.

Saturday morning, Dr. Kim will be discussing the ins and outs of hydrocortisone, how to manage your child's care while they are sick, stress dosing, and how and when to use the emergency injection, Solu-Cortef. Immediately following she will be leading our group in a demonstration and hands-on opportunity to actually mix and inject the Solu-Cortef into oranges.

#### Russell-Silver Syndrome & Small-for-Gestational Age Consultant ~ Dayna Carney Consultant ~ Megan Donnell

All newly diagnosed or first time attending RSS/SGA families should absolutely attend the segment, Understanding RSS/ SGA: The Basics, presented by RSS/SGA Research & Education Director & author of our guidebook, Jennifer Salem. Other families should consider, Living with RSS: UK Research Findings on Adolescents and Young Adults, a presentation of key findings from a UK study on what it is like to live with RSS and the implications for people with RSS, their families and health professionals, by Lisa Marie Hodges, Health Psychologist in Training. Next segment options include Treating Illness & Medical Emergency: What You Need to Know, presented by Dr. Madeleine Harbison. Learn to advocate during unusual circumstances including ketones, blood sugar, managing an ER visit or procedure, and how to use our most essential tool: the Emergency Protocol. Or join Dr. Wendy Coleman for Managing Medically Complex Teens. Our kids face more doctor appointments every year than many of their peers and managing their care can be emotionally draining. After lunch, join Dr. Irène Netchine to learn more about the steps and recommended testing pathway for an undiagnosed IUGR/SGA child. Or attend Practical Nutrition Advice & Managing BMI by RSS mom and certified nutritionist Danielle Binns to learn practical advice about how to meet the nutritional needs of your RSS/SGA child while maintaining the appropriate BMI. Next, join parent and Ph.D. Yvette Getch to learn to advocate for your child under the Individuals with Disabilities Education Act to ensure they receive the services they need during Understanding and Navigating IDEA & Section 504. Come find out your child's rights at school and which plan may best serve your child. Or join Dr. Netchine's colleague, Dr. Béatrice Dubern, from Paris in Gastrointestinal Manifestations and Nutritional Management in RSS/SGA where we will examine the GI issues that are often present and the different ways we can ensure our children are receiving adequate calories for optimal growth.

Saturday morning starts with a presentation for all RSS and SGA families! Drs. Harbison and Netchine will touch on the various issues that our children face using the published consensus statements as a reference. Next, we are VERY excited to have teen motivational speaker Hannah Jordan presenting Odds Don't Determine Outcome. Born SGA and later diagnosed with many additional health issues, at 13 years old she set a simple goal to learn to ride a bike. Two months later she earned a silver medal in the state championship and now 18 months later she has earned 6 gold medals! Bring the whole family for this motivational hour with one of our very own MAGIC kids!

All Weekend: Free Screenings with the esteemed Dr. Harbison are available on a first come basis to RSS/SGA families who are not current patients of Dr. H. After registration is received and processed at MAGIC, Jennifer Salem will contact you.

Our Hypophosphatasia program begins with Dr. Kathryn Dahir and Dr. Jill Simmons who will speak on the diagnosis, treatment, and management of HPP for both children and adults. This will include the importance of accurate diagnosis, genetics, and current treatment options. Dr. Mark Cannon will be giving an overview of the dental aspects of HPP as well as the care and prevention of some of the common problems associated with HPP. Danielle Binns will feature guidelines including what foods to eat and what should be avoided if you have or care for someone with the disorder. Next, Crystal Lee will present about Aquatic therapy (no impact) exercise and strengthening and their importance for both bone and muscle. Finally, we will have a session about durable medical equipment which includes everything from walkers to wheelchairs, but also includes helps and devices which can be used at home and away to make things easier for those with HPP. Make sure to bring your questions and concerns for each presenter.

On Thursday: Free consultations with be available with Drs. Dahir and Simmons on Thursday afternoon on a first come basis. After your registration is received and processed at MAGIC, you will be contacted.

## McCune-Albright Syndrome/Fibrous Dysplasia

We will begin Friday with Dr. Collins of the National Institutes of Health (NIH) discussing endocrine and bone issues in MAS/FD. He will review what causes the syndrome and how to evaluate and treat patients with MAS/FD. He will also discuss how to figure out what aspects of the syndrome your child might have and what aspects your child does not have and won't get. He will also talk about existing and future treatments. Next, Dr. Stanton of Nemours Children's Hospital will discuss the surgical management of fibrous dysplasia in children with MAS. He plans to focus on the need to understand the limitations of current surgical techniques in cases of severe bone disease. He will discuss some of his most difficult cases, including some of his "failures". After lunch, Dr. Burke will be covering the basics of craniofacial FD and what to expect with it. She will also include some dental implications. Our final speaker of the day, will be Dr. Boyce. Dr. Boyce will be focusing on the endocrine issues associated with MAS/FD, including precocious puberty. Saturday morning we will resume with a networking session, so we can get to know each other better. We will have the chance to share stories, resources, and ideas. Our last speaker will be Crystal Lee, who is a PTA with a certification in aquatic therapy. She'll be discussing the benefits of aqua therapy along with different exercises we can do to help ease our pain.

## Optic Nerve Hypoplasia/Septo Optic Dysplasia

We are happy to feature two different sessions with Dr. Mark Borchert. The first session, Optic Nerve Hypoplasia: Anatomy and Vision Consequences, will be a discussion of the relationship of optic nerve formation with the rest of the brain and how abnormal development affects vision as well as the theoretical causes of ONH. Dr. Borchert's second session will review the impact of ONH on growth and development, as well as how to anticipate developmental problems. Our second speaker, Dr. Ellen Connor will also feature two different sessions. Dr. Connor's first session will be "A User's Guide to the Endocrinology of ONH." In this session Dr. Connor will explain how the hypothalamus and pituitary gland are affected with ONH, as well as how to test for hormone problems and what each hormone does. Dr. Connor's second session, "A Weighty Topic for Parents of Children with Hypothalamic Obesity," will discuss the hypothalamus and how it is involved with abnormal weight gain in some children with pituitary problems. We will also learn how the hypothalamus controls appetite and what therapies are being developed to help children with this condition. We are so fortunate to have Joanne Zucker, an adult with ONH and a teacher of the Visually Impaired join us again! Ms. Zucker's topic this year, Transitions: A Part of Life, will discuss focus on issues children with visual impairments face at specific times of change throughout their young lives, known as transitional times. Transitional times include times between Early Intervention Services in the home to preschool outside the home, to entering public school (kindergarten), to entering middle school, to high school, and then into higher education and/or the workforce. Strategies, tips and resources will also be provided to help you support your child through these transitional times, as they move from one chapter to the next in their lives. Since our ONH/SOD children and adults may have multiple hormone issues we are encouraging our families to try to attend other sessions the convention has to offer that may be relevant to their needs. The sessions on Adrenal Insufficiency and how to give Solu-Cortef shots are both important to parents and families with ONH/SOD. Finally we will have many opportunities to join others for conversation. Make sure you take the time to meet and get to know other families and share your common ground!

## www.magicfoundation.org

## Segment Descriptions

#### Hypophosphatasia

Consultant ~ Tracey Porreca

Consultant ~ Tamara Gordon

Consultant ~ Martha Michals

## Friday, July 21, 2017

						• = ·			
	GROWTH HORMONE DEFICIENCY	HYPOPHOSPHATASIA	McCUNE ALBRIGHT SYNDROME/ FIBROUS DYSPLASIA	RUSSELL-SILVER SYNDROME & SMALL-FOR-GESTATIONAL AGE		OPTIC NERVE HYPOPLASIA/ SEPTO OPTIC DYSPLASIA	PANHYPOPITUITARISM/ TUMOR	ADULT GHD/ ADULT PANHYPOPITUITARISM	CUSHINGS
	(GHD)	(HPP)	(MAS/FD)	(RSS/SGA)		(ONH/SOD)	(PAN/Tumor)	(AGHD/PAN)	(CUSH)
9:00 AM	GH Therapy Beyond Height	Hypophosphatasia: Diagnosis, Treatment, and Management (Part 1)	You, Your Child & McCune-Albright Syndrome	Understanding RSS/SGA: The Basics	Living with RSS: UK Adult & Adolescent Research Findings	Optic Nerve Hypoplasia: Anatomy & Vision Consequences	PAN 101	Cortisol Replacement Options	
0:30 AM	Hudson	Dahir	Collins	Salem	Hodges	Borchert	Geffner	Kim	
0:45 AM 2:00 PM	Puberty: When is it Right?	Hypophosphatasia: Diagnosis, Treatment, and Management (Part 2)	Surgical Management for Fibrous Dysplasia	Treating Illness & Medical Emergency: What you Need to Know	Managing the Medically Complex Teen	Systemic and Developmental Impacts of ONH	Sleep Issues in PAN Kids	Living with a Chronic Illness	
	Adkins	Simmons	Stanton	Harbison	Coleman	Borchert	Koren	Gillett, Hadley & Werley	
	·	·		LI	UNCH - 12:00 PM - 1:3	0 PM			
1.30 DM	The Emotions	Understanding the Dental Aspects and Treatment	Craniofacial and Dental Implications of Fibrous	The IUGR/SGA Child: Recommended	Practical Nutrition	A User's Guide to the	How to Enact Emergency Protocols	Pituitary 101	

1:30 PM _	The Emotions of Injections	Understanding the Dental Aspects and Treatment of Hypophosphatasia	Craniofacial and Dental Implications of Fibrous Dysplasia	The IUGR/SGA Child: Recommended Diagnostic Pathway	Practical Nutrition Advice & Managing BMI	A User's Guide to the Endocrinology of ONH	How to Enact Emergency Protocols in Your Area	Pituitary 101
2:45 PM	Gillett, Hadley & Werley	Cannon	Burke	Netchine	Binns	Connor	Madderra	Weber
3:00 PM - 4:15 PM	Prophylactic Administration of Zofran for GH Stim Testing	Diet and Nutrition in Hypophosphatasia	Endocrine & Pubertal Issues in MAS/FD	Understanding & Navigating IDEA & Section 504 for School Aged Children	Gastrointestinal Manifestations and Nutritional Management in RSS/SGA	Transitions: A Part of Life	Managing a Medically Complex Kid	Pituitary 201
	Beauregard	Binns	Boyce	Getch	Dubern	Zucker	Coleman	Katznelson

## Saturday, July 22, 2017

	Geffner	effner Hypophosphatasia Lee		Jordan	Kim	I	Katznelson	Middleman
10:45 AM - 12:00 PM	Q & A	Everyone Needs a Hand: Durable Medical Equipment in	Enhancing Your Life Through the Magic of Aquatic Therapy & Exercise	Odds Don't Determine Outcome	Solu-Cortef Training		Q & A	Surviving Cushings
10:30 AM	Miller	Lee		Netchine & Harbison	Connor	Kim	Rinehart	Katznelson
9:00 AM	Aquatic Therapy and Water Exercise in HypophosphatasiaNetworking		RSS Consensus Overview & the Multidisciplinary Approach to Treating RSS/SGA with Q & A	A Weighty Topic for Parents of Children with Hypothalamic Obesity	Adrenal Insufficiency and How to Save Your Child's Life	Fertility & Sexual Development in Adults with Endocrine Disorders	Cushing's 101	

LUNCH - 12:00 PM - 1:30 PM