

# THE MAGIC FOUNDATION'S 15TH ANNUAL CONVENTION





Celebrating 20 years of Growth!

Foundation established in 1989



JULY 23<sup>\*</sup>, 26, 2009

Westin Chicago North Shore Wheeling, Illinois

### Convention Schedule

### Thursday, July 23, 2009 2:00 - 10:00 pm

- ♦ Registration
- ◆ Exhibits Representatives from numerous companies present their products and have special gifts and games for the kids (and adults!)
- Refreshments will be served
- ◆ Complimentary dental screenings by Dr. Kirt Simmons and Dr. Irwin Seidman for new consults only (Appointment required see registration form)

### Friday, July 24, 2009

| 7:30 am - 9:00 am  | Breakfast (on your own) - Breakfast carts will be available |
|--------------------|---|
| 8:00 am - 12:00 pm | Daycare Open  |
| 8:30 am            | Field Trip departs to Milwaukee County Zoo                  |
| 9:00 am - 12:00 pm | Educational Segments (see centerfold)                       |
| 12:00 pm - 1:00 pm | Lunch (on your own) - Lunch carts will be available         |
| 12:45 pm - 5:00 pm | Daycare open  |
| 1:00 pm - 5:00 pm  | Educational Segments (see centerfold)                       |
| 4:30 pm - 4:45 pm  | Field Trip returns  |
| 6:30 pm            | "Dancing through the Decades Party"                         |

- Pick a decade, dress the part and dance away! (ie: Rock & Roll, Woodstock, Disco, 80's, Hip Hop, etc.)
- Maestro Dworkin will provide a SOUND workout for the Mind, Body and Soul, called Conductorcise ®
- Buffet dinner will be served
- Entertainment provided by DJ

### Saturday, July 25, 2009

| 7:30 am - 9:00 am | Breakfast (on your own) - Breakfast carts will be available |
|-------------------|---|
| 7:30 am - 1:00 pm | Daycare open  |
| 8:00 am - 1:00 pm | Educational Segments (see page 8)                           |
| 1:00 pm           | Lunch (on your own) - Lunch carts will be available         |
| 1:30 pm - 4:30 pm | MAGIC Splash Party - Wheeling Park District Aquatic Center  |
|                   | (food available for purchase at Aquatic Center)             |
| 4:30 pm - 5:30 pm | Grandparents Gathering                                      |
| 6:30 pm           | MAGIC's 20th Birthday Celebration!                          |
|                   |   |

- Party Favors for everyone
- Buffet dinner will be served
- Entertainment provided by DJ

### Sunday, July 26, 2009

10:00 am - 12:00 pm The MAGIC Foundation's Annual Meeting - Open to all!

### Faculty

### Craig A. Alter, M.D.

Clinical Director, Endocrinology The Children's Hospital of Philadelphia Philadelphia. Pennsylvania

#### **Shannon Barrett**

Parent of Affected Child Bluffton, South Carolina

### Cindy Baranoski, MS, RD, LDN

Manager Nutrition Department Pediatric Nutrition Therapist, Feeding Clinic Coordinator Easter Seals DuPage & Fox Valley Region Villa Park, Illinois

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

Head, CHLA Division of Ophthalmology Associate Professor of Clinical Ophthalmology & Neurology USC, Keck School of Medicine Los Angeles, California

### Brian Bordini, M.D.

Instructor in Pediatrics Pediatric Endocrinology The University of Chicago Comer Children's Hospital Chicago, Illinois

### David R. Brown, M.D., F.A.C.E.

Pediatric Endocrinology and Metabolism Staff Physician Children's Hospitals and Clinics Clinical Professor, Department of Pediatrics University of Minnesota Minneapolis, Minnesota

### **Lindsey Carmichael**

2008 Bronze Medalist Paralympic Archer University of Texas Austin. Texas

### Antonio H. Chaviano, M.D.

Pediatric Urologist Northwestern University Feinberg School of Medicine Children's Memorial Hospital Chicago, Illinois

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

Chief, Skeletal Clinical Studies Unit National Institutes of Health Bethesda, Maryland

### Ellen L. Connor, M.D.

Associate Professor UW Hospital - Clinical Science Center Madison, Wisconsin

### Johnna Darragh, Ph.D.

Professor of Early Childhood Education Illinois Liaison to the National Professional **Development Center on Inclusion** Bloomington, Illinois

### Gina Ford, RPh. MBA

Sr. Director, Reimbursement & Patient Svcs Tercica, Inc US Subsidiary of Ipsen Group Brisbane, California

### Sherry L. Franklin, M.D.

Pediatric Endocrinology of SD Med. Group Rady Children's Hospital of San Diego Assistant Clinical Professor at UCSD San Diego, California

#### Pamela Garcia-Filion, MPH

Clinical Research Associate Children's Hospital Los Angeles Los Angeles, California

### **Tamera Garrett**

Parent of Affected Child St. Charles, Illinois

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

Professor of Pediatrics Director of Fellowship Training Div of Endocrinology/Diabetes/Metabolism The Saban Research Institute Childrens Hospital Los Angeles Keck School of Medicine of USC Los Angeles, California

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

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

### Christopher Peter W. Houk, M.D., F.A.A.P.

Associate Professor of Pediatrics Medical College of Georgia Augusta, Georgia

### Char Laursen, MS, CCC-SLP

Pediatric Speech/Language Pathologist Therapeds, Ltd. Naperville, Illinois

### Janice S. Lee, D.D.S., M.D., M.S.

Craniofacial Surgeon & Dentist University of California, San Francisco San Francisco, California

### Peter A. Lee, M.D., Ph.D.

Professor of Pediatrics Penn State College of Medicine The Milton S. Hershey Medical Center Hershey, Pennsylvania

Indiana University School of Medicine The Riley Hospital for Children Indianapolis, Indiana

### Nancy Mansfield, Ph.D.

Executive Director, Institute for Families Childrens Hospital Los Angeles Los Angeles, California

#### Kurt Midyett, M.D.

Assistant Professor of Pediatrics Section of Endocrinology/Diabetes Medical Director, Children's Diabetes Center Children's Mercy Hospitals & Clinics Kansas City, Missouri

### Thomas W. Phelan, Ph.D.

Clinical Psychologist ParentMagic, Inc. Glen Ellyn, Illinois

### Robert Rapaport, M.D.

Professor of Pediatrics Emma Elizabeth Sullivan Professor of Pediatric Endocrinology and Diabetes Director, Division of Pediatric Endocrinology and Diabetes

Mount Sinai School of Medicine New York, New York

#### **Caroline Reeb**

Affected Adult Mooresville, North Carolina

#### Ron G. Rosenfeld, M.D.

Professor and Chair (emeritus) of Pediatrics Oregon Health & Science University Portland, Oregon

#### Lauren Ruotolo

**Director of Entertainment Promotions Hearst Corporation** New York City, New York

### Jennifer Salem

Parent of Affected Child Manhattan Beach, California

### David E. Sandberg, Ph.D.

Associate Professor and Director, Division of Child Behavioral Health Dept of Pediatrics/Communicable Diseases University of Michigan Medical School Taubman Health Care Center Ann Arbor, Michigan

### Traci Lynn Schaeffer, RN, BSN

Univ. Of Oklahoma Health Sciences Center Oklahoma City, Oklahoma

### Irwin M. Seidman, D.D.S

Pediatric Dentist Assistant Professor Department of Pediatric Dentistry Univ. of IL - Chicago, College of Dentistry Palatine, Illinois

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

Craniofacial Orthodontist Arkansas Children's Hospital Little Rock, Arkansas

#### Christina M. Southern Reh, M.D.

Div of Endocrinology/Diabetes/Metabolism Childrens Hospital Los Angeles Keck School of Medicine of USC Los Angeles, California

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

Surgeon In Chief Pediatric Orthopedics Nemours Children's Clinic Pensacola, Florida

### Amy Wisniewski, Ph.D.

Co-Director Fellowship Training Program Section of Pediatric Diabetes/Endocrinology The University of Oklahoma Health Sciences Center Oklahoma City, Oklahoma

### Friday Segment Descriptions

# Congenital Adrenal Hyperplasia (CAH) Consultant ~ Cathy Kusch

Dr. Sherry Franklin will discuss anatomy, regulation and hormones produced by the adrenal gland. How did my child get congenital adrenal hyperplasia? Diagnosis, monitoring and treatment. Amy Wisniewski, Ph.D will discuss several aspects of CAH that are predicted to cause stress and anxiety for parents of affected children. Including the life-threatening aspect of this condition, the need for daily medications and frequent clinic visits, and surgical management for some girls. Amy, along with Traci Schaeffer, RN, will describe the development of an interdisciplinary clinic for children and adults affected by 21-hydroxylase deficiency. The disciplines involved include pediatric endocrinology, pediatric urology, child psychiatry and nursing. Dr. Chaviano will discuss the Steps to Understanding Genital Ambiguity, including: Does my child really need this surgery, and what are my surgical options? When should the surgery be done and would it ever have to be done again? Who does a parent talk to when they are having difficulty with this decision? What's new in genital surgery for our CAH daughters? An explanation of management protocols will be offered. David Sandberg will discuss the outcome of a symposium addressing the new diagnostic category of *Disorders of Sex Development* (DSD) that was held at the University of Michigan in April, 2009. The goal of the Symposium was to create a vision for research on caring for persons with DSD (including congenital adrenal hyperplasia), and their families, that will guide recommendations for an interdisciplinary research agenda and learning agenda.

# Growth Hormone Deficiency (GHD) Consultant ~ Courtney Rivard

Dr. Craig Alter is kicking off the day with a presentation called *The Evolution of the Pituitary Gland*. He will be discussing how this master gland impacts our children's growth hormone deficiency as well as other hormones. This is excellent information to have both now and for the future as our children age. Dr. Ellen Connor will present *What to expect during GH Therapy*. What is catch up growth and what is normal catch up growth? What do doctors look for during appointments (IGF1 levels, etc.) Is GH increased during puberty? Does it cause puberty to come about faster? How often do we need to check my child's bone age before or during puberty? When my child's bones are closed, do I need to have my child retested? If so, when and how often? Dr. Kirt Midyett will discuss *Long-Term Effects and Implications of GH Therapy*. This will give families a larger view of the issues and lives of children diagnosed with Growth Hormone Deficiency. And as the new information continues to develop, and our children become adults, this information will be great for those who are concerned about their child's prognosis for the future. Closing the day we have Tamera Garrett giving *A Parent's Perspective: Raising a Growth Hormone Deficient Child*. Being small and having special medical concerns may bring about special circumstances for parents and families. Having a parent who has been through the entire process share their experience will give us all a heads up on how to help our children.

# Insulin-Like Growth Factor Deficiency (IGFD) Consultant ~ Jamie Sorensen

Insulin like growth factor 1 (IGF-1) is a hormone produced primarily in the liver. It is a critical hormone for bone and tissue growth. A deficiency of IGF-1 can cause not only short stature but have other effects as well. In the *Basics of IGFD*, Dr. David R Brown will introduce what IGF-1 is, what it does and why it is so important. He will discuss some of the causes of IGFD and what implication they can have on our growing children. Next Dr. Ron Rosenfeld will be discussing different treatment options in detail and giving an overview on how each one affects the body. Many parents are confused about the treatment options for IGFD. The choice is not always simple to make. There are a couple different options and they all involve different things. Insurance is the second battle we have to overcome after our children receive the diagnosis of IGFD. It can be hard to understand what coverage we have and what our options are if that coverage is not sufficient. Gina Ford from Tercica will be talking and answering your questions in regards to handling your insurance company and how Tercica can help. As parents we know what it is like for us watching our children struggle with IGFD. Carrie Reeb is going to let us know what it was like to be the child growing up with IGFD. Ms. Reeb was in the very first trial study of Increlex almost 15 years ago. She took Increlex as a child and is going to present her story of growing up with IGFD. She will answer any questions that you may have. Her mother Linda Reeb will also be available to answer questions as well. The day will end with a group networking session.

# McCune-Albright Syndrome/Fibrous Dysplasia (MAS/FD) Consultant ~ Catherine Calhoun

Dr. Collins will begin by discussing endocrine and bone issues in MAS. He will review what causes the syndrome and how to evaluate and treat patients with MAS. He will also discuss how to figure out what aspects of the syndrome your child might have, and what aspects of the syndrome your child doesn't have and won't get. He will also talk about existing treatments and potential treatments in the future. Next, Dr. Stanton will discuss the surgical management of fibrous dysplasia in children with McCune-Albright Syndrome. 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 "failures." After lunch, Dr. Janice Lee, craniofacial surgeon and dentist from the University of California at San Francisco, will review the current knowledge and literature on craniofacial fibrous dysplasia, describe the research that has been done in this area, and review surgical management for this condition. Lindsey Carmichael, a young adult with MAS/FD, will discuss her personal experiences with disabled sports and how she made it to bronze at the 2008 Beijing Paralympics. The day will end with a group networking session.

### Optic Nerve Hypoplasia/Septo Optic Dysplasia (ONH /SOD) Consultant ~ Rachel Steen

Dr. Borchert and Pamela Garcia-Fillion will present ONH and *Stem Cells Transplants*. What is the Real Deal? China is advertising stem cells to help improve eyesight for kids with ONH. Can it really be true? What are the risks? What are the benefits? Who do you believe? After lunch Nancy Mansfield, Ph.D. will discuss *How to Talk to Your Children about ONH*. Your child has ONH, how to talk to your other children? What information should you share and how do you share it? Nancy is part of the team working on the ONH study. She has worked as a Pediatric Neuro-Psychologist for over 20 years. She has amazing insight and a video that will not leave a dry eye in the room! Dr. Ellen Connor will then present, *Here a Test, There a Test, Everywhere a Test!* The body has all these hormones, how do you keep track of them all? How do you know what to ask for and when to push harder? Dr. Connor will explain what the hormones do, what tests to have and how to stay on top of everything. The day will end with a group networking session.

# Panhypopituitarism/Tumor (PAN/Tumor) Consultant ~ Janet Meehan

Dr. Geffner will provide a comprehensive overview of the development and anatomy of pituitary gland development, the normal function of the hypothalamic-pituitary unit, the causes of hypopituitarism, the clinical presentation of patients with hypopituitarism, the diagnosis of relevant hormone deficiencies, and the treatment of resultant hormone abnormalities. This will be followed by break-out sessions for the congenital/younger patients (0-7 yr) led by Dr. Geffner and for acquired/older (8+) adolescent/transition age patients led by Dr. Southern Reh. In all sessions, a compassionate, up-to-date approach will provide scientific background, practical information, and hope for the future. After lunch, Dr. Franklin will address the issues of puberty and fertility, and some of the unique challenges faced by those with panhypopituitarism. The presentation will include information for all groups: congenital and acquired, boys and girls. Dr. Simmons presentation will focus on the dental and orthodontic problems and issues individuals with panhypopituitarism are likely to face. End the day with Dr. Southern Reh and Janet Meehan, Division Consultant, for a discussion on how to handle emergency situations for the panpit child. Practice mixing and giving emergency Solucortef shots. Learn the signs of adrenal insufficiency; know what materials and information to keep on hand at home and at school in case of emergencies, and what to take to the ER should you have to go. Get tips on how to set up an emergency plan with your local EMT services, and ask general questions in this informal session.

# Precocious Puberty (CPP) Consultant ~ Denise de Reyna

Together, Drs. Lee and Houk will present three informal segments pertaining to Precocious Puberty. In the first segment, Drs. Lee and Houk will provide responses to the ten most frequently asked questions about Precocious Puberty and its treatment to include: impact upon your child, long-term effects, and whether to treat. Note: Precocious Puberty often requires that parents really face for the first time that their child is a sexual being. Next, *Growth at Puberty-An Overview*, will include hormone changes and body changes including body composition (muscle, fat and bone mass). This will be followed by a discussion of how this is altered when puberty begins too soon. To include general factors including how tall a child is likely to become with or without treatment. After lunch the doctors will present *Hormones and Pubertal Development*. This will be a summary of the causes of early puberty both as a consequence of normal factors activated early or because of uncontrolled hormone stimulation. Medical therapies concerning how to stop puberty and how to help growth and adult height will be discussed. Dr. Bordini will discuss the importance of accurate sex hormone assays, time-of-day variation in hormone levels, GnRHag-stimulation testing and possible sleep testing. He will also explain the differences between true central precocious puberty and incomplete precocious puberty. The day will end with a group networking session.

|                           | Growth<br>Hormone<br>Deficiency<br>(GHD)                         | Insulin-Like<br>Growth Factor<br>Deficiency<br>(IGFD) | Optic Nerve<br>Hypoplasia/<br>Septo Optic<br>Dysplasia<br>(ONH/SOD) | Panhypopituitarism/<br>Tumor<br>(PAN/Tumor)                  |                                     | Congenital<br>Adrenal<br>Hyperplasia<br>(CAH)  |
|---------------------------|--|---|---|--|-------------------------------------|--|
| 9:00 AM<br>-<br>10:30 AM  | Evolution<br>of the<br>Pituitary Gland                           | Basics<br>of<br>IGFD                                  | ONH and<br>Stem Cell<br>Transplants                                 | Hypopituitarism:<br>From A to Z                              |                                     | Basics<br>of CAH   |
|                           | Craig A.<br>Alter, MD  | David R.<br>Brown, M.D.                               | Mark S.<br>Borchert, M.D.   | Mitchell E.<br>Geffner, M.D.                                 |                                     | Sherry L.<br>Franklin, M.D.  |
| 10:45 AM<br>-<br>12:00 PM | What to Expect<br>During<br>Growth Hormone<br>Therapy            | Treatment<br>Options<br>for<br>IGFD                   | ONH Clusters:<br>Do They Exist?<br>What Does All the<br>Data Mean?  | Issues Faced in the Early Years of Ages 0-7                  | Transition Years: Ages 8+ Christina | Parenting Styles in<br>Families Affected<br>by CAH:<br>A Close Look at<br>Stress and Anxiety |
|                           | Ellen L.<br>Connor, M.D.   | Ron G.<br>Rosenfeld, M.D.                             | Pamela Garcia-<br>Filion, MPH                                       | Mitchell E.<br>Geffner, M.D.                                 | Southern<br>Reh, M.D.               | Amy<br>Wisniewski, Ph.D.   |
| Noon – 1                  |  |   | LUNCH   |  |                                     |  |
| 1:00 PM<br>-<br>2:30 PM   | Long-Term Effects and Implications of Growth Hormone Therapy     | Insurance<br>and<br>Reimbursement<br>Help             | How to Talk to<br>Your Children<br>About ONH                        | Sex, Fertility<br>and Puberty<br>Sherry L.<br>Franklin, M.D. |                                     | Improving Clinical Experiences for Children & Families Affected by CAH                       |
|                           | Kurt<br>Midyett, M.D.  | Gina Ford,<br>RPh, MBA                                | Nancy<br>Mansfield, Ph.D.   |  |                                     | Amy<br>Wisniewski, Ph.D.<br>Traci Lynn<br>Schaeffer, RN, BSN                                 |
| 2:45 PM<br>-<br>4:00 PM   | A Parent's Perspective: Raising a Growth Hormone Deficient Child | Life<br>with<br>IGFD                                  | Here a Test,<br>There a Test,<br>Everywhere a<br>Test!              | Panhypopituitarism:<br>What's Teeth Got<br>To Do With It?    |                                     | Steps to<br>Understanding<br>Genital<br>Ambiguity  |
|                           | Tamera Garrett   | Caroline Reeb   | Ellen L. Caroline Reeb Connor, M.D.                                 |  | t E.<br>s, D.D.S.                   | Antonio H.<br>Chaviano, M.D.   |
| 4:00 PM<br>-<br>5:00 PM   | Networking   | Networking  | Networking  | How to Handle<br>Emergency Situations<br>&<br>Networking     |                                     | Vision for a New<br>Research Agenda<br>and Improved<br>Model of Care                         |
|                           |  |   |   |  |                                     | David E.<br>Sandberg, Ph.D.  |

| McCune-Albright Syndrome/ Fibrous   | Precocious<br>Puberty   | Russell-S<br>Syndro   | Small for<br>Gestational Age                                |  |
|---|---|---|---|--|
| <b>Dysplasia</b><br>(MAS/FD)  | (CPP)   | (RSS  | (SGA)   |  |
| Endocrine and Bone Issues in Children   | Frequently Asked Questions About CPP  | Adolescence:<br>An Open<br>Discussion   | Treating RSS/SGA:<br>Dr. Harbison's Protocol                |  |
| with MAS/FD  Michael T. Collins, M.D.   | Peter A. Lee, M.D., Ph.D. & Christopher Houk, M.D.                                    | Jennifer<br>Salem   | Madeleine D. Harbison, M.D.                                 |  |
| Surgical Expectations in MAS  Robert P.                                       | Growth at Puberty: An Overview  Peter A. Lee, M.D., Ph.D. & Christopher               | It's All About Teeth  Kirt E. Simmons, D.D.S., Ph.D.  | Common Gut Dysmotility Problems and Solutions  Madeleine D. | Getting to Know Each Other: An SGA Parents Perspective and Chat Session Shannon  |
| Stanton, M.D.   | Houk, M.D.  | LUNCH   | Barrett   |  |
| Updates in Craniofacial Fibrous Dysplasia  Janice S. Lee, D.D.S., M.D.        | Hormones and Pubertal Development  Peter A. Lee, M.D., Ph.D. & Christopher Houk, M.D. | Feeding and Nutrition for the Underweight Child  Cindy Baranoski, MS, RD, LDN & Char Laursen, MS, CCC-SLP |   | Growth and Non-Growth Related Issues in Children Born SGA  Robert Rapaport, M.D. |
| Growing Up with MAS and Winning Bronze at the Paralympics  Lindsey Carmichael | Evaluation for Precocious Puberty Brian Bordini, M.D.                                 |   |   | Panel Discussion:<br>Our Older Children:<br>What Works,<br>What Doesn't          |
| Networking  | Networking  | Phenotype/Genotype Study Update<br>and Q&A<br>All Presenters  |   |  |

### Friday Segment Descriptions (continued)

# Russell-Silver Syndrome (RSS) Consultant ~ Dayna Carney

A diverse line up is offered that includes topics for the newly diagnosed as well as adolescents and teens. In the morning, families can choose Dr. Harbison's treatment protocol for RSS/SGA children (a MUST for any new family!). In this segment Dr. Harbison will discuss the treatment options available for RSS/SGA children, and how she utilizes these options to maximize the health and growth of her ever growing patient base of over 120 RSS/SGA children. Next will be a presentation on the common gut dysmotility issues our children face including reflux, delayed gastric emptying, constipation and g-tubes. Families of older children may prefer the open discussion on adolescent issues moderated by Jennifer Salem, primary author of the infamous Guidebook, and the segment with Dr. Kirt Simmons about our children's unique dental issues. After lunch, join Cindy Baranoski and Char Laursen for an extended session to help us cope with the unique feeding issues of our children as well as advice on how to ensure good nutrition and adequate weight gain simultaneously! Finally, although Dr. Netchine is unable to join us this year, Dr. Harbison will be briefly updating us on the progress of their phenotype/genotype study with MAGIC! We will end our day with a question and answer session with the presenters.

# Small-for-Gestational Age (SGA) Consultant ~ Shannon Barrett

Dr. Harbison will discuss the treatment options available for RSS/SGA children, and how she utilizes these options to maximize the health and growth of her ever growing patient base of over 120 RSS/SGA children. Next come meet your new division consultant and network with other SGA families. After lunch, Dr. Rapaport will discuss not only growth but other concerns affecting children born with SGA. Growth is an important factor for children born SGA, but there are important issues other than growth alone. Next our focus is on the older children. As our children prepare to enter junior high and high school, the issues facing our children evolve. Come network and share with other parents dealing with the same issues (for parents of children 8 years of age and up). The day will end with a brief update on the progress of Dr. Harbison's phenotype/genotype study with MAGIC and a question and answer session with the presenters.

### Saturday Segments

|          | ALL DIVISIONS WELCOME                             |   |  |  |  |
|----------|---|---|--|--|--|
| 8:00 AM  | No Limits   | Advocating for Social Inclusion   |  |  |  |
| 9:00 AM  | Lauren Ruotolo                                    | Johnna Darragh, Ph.D.   |  |  |  |
| 9:00 AM  | Dental Issues Associated with<br>Growth Disorders | More 1 - 2 - 3 Magic Parenting  |  |  |  |
| 10:00 AM | Kirt E. Simmons, D.D.S.                           | Thomas W. Phelan, Ph.D.   |  |  |  |
| 10:15 AM | Growth Disorders When Our Children Become Adults  | Understanding Disorders of Sex Development:<br>How We Can Help Our Children |  |  |  |
| 11:30 AM | David R. Brown, M.D.                              | Amy Wisniewski, Ph.D.<br>David E. Sandberg, Ph.D.                           |  |  |  |
| 11:45 AM | New Diagnostic and<br>Treatment Paradigms         | Discussion About Disorders of Sex Development                               |  |  |  |
| 1:00 PM  | Ron G. Rosenfeld, M.D.                            | Amy Wisniewski, Ph.D.<br>David E. Sandberg, Ph.D.                           |  |  |  |

### Saturday Segment Descriptions

### **No Limits**

Lauren Ruotolo lives her life with no limits walking red carpets and jetting between coasts. She is an adult with a growth condition (McCune-Albright) who with hard work and an unstoppable attitude has it all -great job, great friends, great guy and great shoes! Lauren will share the secrets to her success with MAGIC families.

### **Advocating for Social Inclusion**

This presentation will provide information designed to guide parents in their role as social inclusion advocates who work to ensure each aspect of the educational environment supports their child's healthy social and emotional development, including relationships with peers and overall belonging within the classroom community. Children with disabilities are entitled to a free and appropriate education with their peers in natural settings; however, a failure to attend to individual and community needs regarding social inclusion can create problematic situations for young children's self image and self esteem. In addition, strategies supporting social inclusion not only benefit those children who meet federal guidelines for a disability, but all children within educational environments. Participants will learn how to effectively advocate for their child, and also learn specific strategies to help others ensure that their child is a vibrant part of the classroom community.

### **Dental Issues Associated with Growth Disorders**

Dr. Simmons will discuss the growth and development of the teeth, mouth and face and how these processes can be affected by growth disturbances. He will give specific examples that may be associated with particular growth disorders. Unfortunately most dentists and many physicians are unaware of these issues, making this information especially valuable for parents.

### More 1 - 2 - 3 Magic Parenting

Dr. Phelan will explain how to get your children to do the good things you want them to do, such as getting up and out in the morning, eating, going to bed and picking up after themselves. You will also learn practical, down-to-earth strategies for encouraging your children's growing independence and for promoting reasonable, healthy self-esteem.

### **Growth Disorders... When Our Children Become Adults**

Attaining final stature may not be the end of issues related to your child's growth disorder. Many adults treated in childhood may require additional treatment for non growth related issues. Growth hormone has significant biological effects which influence many body systems including the skeletal, muscle, fat and protein metabolism. Dr. Brown will review issues related to growth hormone and IGF1 after growth is complete. In addition to biological issues many young adults with growth disorders may have psychological or behavioral issues which needs to be further addressed. Many patients in whom the growth disorder was a manifestation of any systemic condition or a consequence of a intracranial neoplasm may have additional issues that persist into adulthood. Remember our children grow up in age and maturity as well as stature, we need to be prepared for it!

### Understanding Disorders of Sex Development: How We Can Help Our Children

A brief overview of DSD will be provided. Also, an update on the latest research efforts will be described and what parents can take away from this research. There will be an emphasis on what parents can actively do to help their children adjust to DSD.

### **New Diagnostic and Treatment Paradigms**

For many years research has changed the diagnostic and treatment options for children with growth disorders. Current techniques provide the most encouraging and effective diagnostic and treatment protocols available today. Dr. Rosenfeld will discuss the future of growth hormone.

### **Discussion About Disorders of Sex Development**

This discussion will be driven by the interests of the group. In the past, such topics as body image, talking about DSD, surgical options, and fertility challenges have been discussed.

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### <u>Program Details</u>

### 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, provide product samples 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 and Dr. Irwin Seidman, will be available for complimentary dental consultations. Appointments are mandatory and will last approximately 10 minutes. Appointments are made on a first come, first served basis and are open to **new consults only**. You will be notified by mail regarding your appointment status. See registration form to make an appointment.

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

Adult-chaperoned field trip to the Milwaukee County Zoo. Cost per child includes admission, transportation and a pizza lunch. Children must be 6 years or older, unless accompanied by an adult family member. For additional information on the Milwaukee County Zoo, visit their website at www.milwaukeezoo.org

### Daycare (Friday & Saturday)

The cost per child covers professional daycare (at the hotel) during the educational segments all day Friday and Saturday morning. Children must be picked up at daycare by noon on Friday. Daycare is closed during lunch and will re-open at 12:45 pm. If you have children going into daycare, you must pre-register them with American ChildCare Services. Pre-registration can be done via their website, <a href="www.americanchildcare.com/magic">www.americanchildcare.com/magic</a>, or by calling 312-644-7300 to obtain forms. Pre-registration will also be available on Thursday during exhibit hours.

### <u>Dancing through the Decades Party (Friday)</u>

Pick a decade, dress the part and dance away! Maestro David Dworkin will provide a program of movement and musical education based on the art of conducting called Conductorcise®, a SOUND workout for Mind, Body and Soul. For more information on Maestro Dworkin and Conductorcise®, visit <a href="www.conductorcise.com">www.conductorcise.com</a>. Buffet dinner will be served.

### MAGIC Splash Party—Wheeling Park District Aquatic Center (Saturday)

Join the MAGIC group at a unique water park located nearby the Westin Hotel. MAGIC families will receive a discounted admission rate of \$9 per person. Lunch is not provided, but concession stands are available at the park. Some amenities include: slides, lap lanes, sand volleyball, diving board, water playground with large tipping bucket and much, much more. Transportation will be provided by the hotel. For additional information on the aquatic center you can visit their website at <a href="http://www.wheelingparkdistrict.com/Aquatics/AC-amenities.htm">http://www.wheelingparkdistrict.com/Aquatics/AC-amenities.htm</a>

### **Grandparents Gathering (Saturday)**

Meet with other grandparents to discuss your role in your grandchild's life.

### MAGIC 's 20th Birthday Celebration (Saturday)

MAGIC is celebrating it's 20th birthday this year! Help MAGIC celebrate 20 years of support and education to families! A Buffet dinner will be served and we will also have party favors, birthday cake, DJ and FUN for ALL!

### MAGIC Annual meeting (Sunday)

Come join the Board of Directors for an update on MAGIC's activities & future plans. Everyone is 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.

### General Convention Information

### **Dates**

Thursday, July 23 - Sunday, July 26, 2009

### Location

Westin Chicago North Shore 601 N. Milwaukee Avenue, Wheeling, IL 60090 (847) 777-6500

### **Convention Registration Fee**

\$155 per immediate family for MAGIC members. This fee includes two adults and unlimited children. \$190 per immediate family for non-members. Non-members will receive a 1-yr membership to MAGIC. Additional adults are \$20 each (grandparents, aunts/uncles, friends, etc.) Additional "Grandparents for Growth" members are only \$10 each

### **Daycare**

American ChildCare Services will be providing professional daycare at MAGIC's convention. The cost is \$60 per child. This is a flat fee which covers Friday and/or Saturday. Pre-registration is necessary and can be done via their website, <a href="www.americanchildcare.com/magic">www.americanchildcare.com/magic</a> 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.

### Registration Deadline/Refund Policy

Registration fees and forms are due by July 1, 2009. Any registrations received after this time will be charged a late fee of \$25. There will be no refunds after July 1st.

### **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.

### **Hotel Room Rates and Reservations**

\$ 97 per night (tax not included)

### Refrigerators available upon request

Also available: Roll-a-Ways (\$10 per night); Cribs (\$17 per night). To make hotel reservations call the Westin at 800-937-8461, and mention The MAGIC Foundation guest room block, or book online at: <a href="http://www.starwoodmeeting.com/StarGroupsWeb/res?id=0812102687&key=A8276">http://www.starwoodmeeting.com/StarGroupsWeb/res?id=0812102687&key=A8276</a>

### **Airline Transportation**

Please contact your local travel agent or search the internet for the most reasonable price. Be sure to search often and book early as great fares sometime become available. The airport of choice is O'Hare (ORD) which is located closer to the hotel. Midway (MDW) is in Chicago also but a distance from the hotel. Please read "hotel transportation" below before booking a flight to Midway.

### **Hotel Transportation**

Free shuttle service is provided to the Westin Chicago North Shore from O'Hare Airport only!

The shuttle schedule is as follows:

O'Hare Airport to the Westin - **Thursday** - 11 am, 1 pm, 3pm, 5pm and 7 pm
Westin to O'Hare Airport - **Sunday** - Pickups at 8 am, 10 am, noon, 2 pm and 4 pm
If arriving outside of the shuttle times you will need to arrange your own transportation to the hotel.
Shuttle buses will have a MAGIC Foundation/Westin Chicago North Shore sign in the window
O'Hare pick-up locations are as follows:

### Terminal 1, Door 1G \* Terminal 2, Door 2E \* Terminal 3, Door 3H \* Int'l Terminal, Door 5D

If you are unable to find the shuttle, you can contact Eved Services Dispatch at 866-922-3833.

You may choose to arrive at Midway Airport. If you do there is no free transportation available. A taxi ride is costly. If your only option is to arrive at Midway Airport, consider Omega Airport Shuttle service to O'Hare and then catch the shuttle to the Westin. The fare is \$16 each way per person. For additional information visit their website, www.omegashuttle.com, or call 773-734-6688.



# Convention Registration Form

| ames of adults attending: (FIRST & LAST for everyone)                       |                | Disorder:         |                  |                 |  |
|---|----------------|-------------------|------------------|-----------------|--|
| 2   |                | Address:          |                  |                 |  |
| 4   |                | Address:          |                  |                 |  |
| mes of Children Attending Age M/F   |                | City:             | St:              | Zip:            |  |
|   |                | Country:          | Phone:           |                 |  |
|   |                | E-mail:           |                  |                 |  |
|   |                | Endocrinologist N | ame/City:        |                 |  |
| SATURDAY  (Sessions run concurrent)   |                |                   |                  | 5SGA            |  |
| (write # attending in box)  | 8:00 - 9:00 an | 9:00 –10:00 am    | 10:15 - 11:30 am | 11:45 - 1:00 pm |  |
| No Limits   |                | NA                | NA               | NA              |  |
| Advocating for Social Inclusion   |                | NA                | NA               | NA              |  |
| Dental Issues Associated with Growth Disorders                              | NA             |                   | NA               | NA              |  |
| More 1 - 2 - 3 Magic Parenting  | NA             |                   | NA               | NA              |  |
| Growth Disorders<br>When Our Children Become Adults                         | NA             | NA                |                  | NA              |  |
| Understanding Disorders of Sex Development:<br>How We Can Help Our Children | NA             | NA                |                  | NA              |  |
| New Diagnostic and Treatment Paradigms                                      | NA             | NA                | NA               |                 |  |
| Discussion About Disorders of Sex Development                               | NA             | NA                | NA               |                 |  |



| Activity   | Cost   | # Attending            | <b>Total Cost</b>    |  |  |  |
|--|--|------------------------|----------------------|--|--|--|
| THURSDAY   |  |                        |                      |  |  |  |
| Registration  ◆ Members  ◆ Non-Members  ◆ Additional Adults*  ◆ Additional "Grandparents for Growth" Members   | \$155 per family<br>\$190 per family<br>\$20 each<br>\$10 each |                        | \$<br>\$<br>\$<br>\$ |  |  |  |
| Registration fee includes 2 adults and unlimited children. *Addi   | tional adults may includ                                       | le: grandparents, aunt | s/uncles or friends  |  |  |  |
| FRIDAY   |  |                        |                      |  |  |  |
| Daycare  ◆ \$60 per child  Flat fee includes both Friday and Saturday  | Friday<br>Saturday<br>Friday & Saturday                        |                        | \$                   |  |  |  |
| If you have children attending daycare, you must pre-register with American ChildCare<br>Services. See General Convention Information for additional information.  |  |                        |                      |  |  |  |
| Field Trip - Milwaukee County Zoo (6 years or older)   | \$40 per person  |                        | \$                   |  |  |  |
| Name/Age of <b>child</b> attending trip: 1 2 3 4   |  |                        |                      |  |  |  |
| MAGIC Dancing through the Decades Party  ◆ Buffet dinner included  | \$12 Ages 12+<br>\$ 9 Ages 2 - 11<br>Under 2 - FREE            |                        | \$<br>\$<br>FREE     |  |  |  |
| SATURDAY   |  |                        |                      |  |  |  |
| Grandparents Gathering   | FREE   |                        | FREE                 |  |  |  |
| MAGIC Splash Party - Wheeling Park District Aquatic Center   | \$9 per person<br>(under 3 - FREE)                             |                        | \$                   |  |  |  |
| MAGIC's 20th Birthday Celebration!  • Buffet dinner included   | \$12 Ages 12+<br>\$ 9 Ages 2 - 11<br>Under 2 - FREE            |                        | \$<br>\$<br>FREE     |  |  |  |
| SUNDAY   |  |                        |                      |  |  |  |
| MAGIC Annual Meeting   | FREE   |                        | FREE                 |  |  |  |
|  | (If after July 1st, add  | LATE FEE of \$25)      | \$                   |  |  |  |
| Total Payment Enclosed \$  |  |                        |                      |  |  |  |
| Note: MAGIC will be taking pictures throughout the convention. Your participation in The MAGIC Foundation's 15th Annual Convention gives us permission to use these pictures in our scrapbooks, website and other publications. If you do not want MAGIC using your photographs you need to send a written request to MAGIC. |  |                        |                      |  |  |  |
| MAGIC accepts Visa, MasterCard and Discover. If you wish to pay by credit card please complete the following:  |  |                        |                      |  |  |  |
|  | Expiration Date Total \$                                       |                        |                      |  |  |  |
| Cardholder Name Signature  |  |                        |                      |  |  |  |

Return completed registration form by July 1, 2009 to: MAGIC Foundation, 6645 W. North Avenue, Oak Park, IL 60302 or fax to 708-383-0899



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



### Celebrating MAGIC's 20th Birthday!



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

### Disorders to be covered:

Congenital Adrenal Hyperplasia
Disorders of Sex Development
Growth Hormone Deficiency
Insulin-Like Growth Factor Deficiency
McCune-Albright Syndrome/Fibrous Dysplasia

Optic Nerve Hypoplasia/Septo Optic Dysplasia
Panhypopituitarism/Tumor
Precocious Puberty
Russell-Silver Syndrome
Small-for-Gestational Age

The MAGIC Foundation
6645 W. North Avenue, Oak Park, IL 60302
708-383-0808, 708-383-0899 FAX, 800-3 MAGIC 3
www.magicfoundation.org

"Children have a short time to grow and a lifetime to live with those results"®