

The 5th International Symposium on APS Type 1



Friday, July 7, 2023 - Saturday, July 8, 2023
Melrose Georgetown Hotel
Washington, DC



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Welcome Message from the President

Welcome to our 5th International Symposium on APS Type 1!

I first want to thank our physician and scientist colleagues for taking time out of their busy schedules to spend time with the patients, families, friends and caregivers of our community. We have a lot to share with you. I also want to thank our patients, families, friends and caregivers for prioritizing this weekend to hear about the latest research, discuss the challenges we all face managing this disorder, and welcome new families by sharing experiences with one another. Speaking with those that have walked the road you have yet to travel is a great way to prepare your loved ones for a positive journey ahead.

Living an ordinary life is extraordinary. Although we all face challenges from time to time, we all desire the same thing, namely an opportunity to have an ordinary life. The APS Type 1 Foundation and our incredible board remain committed to achieving our mission of driving awareness, supporting education, and looking for opportunities to fundraise for continued research. One day we will find a cure. In the meantime, we have each other, and together we are making an impact. I would also like to take a moment to thank our generous sponsors and donors, including the Lovett family, Combe Incorporated, Sanguine Biosciences Incorporated, and Julia's Fund at the SickKids Foundation, for making this event possible.

Enjoy the conference, ask questions, and meet new people. We are here to support you, and we look forward to engaging dialogues. Thank you for joining us!



Todd Talarico

Todd S. Talarico
President, APS Type 1 Foundation



Agenda

Thursday, July 6, 2023

Venue: William Penn, Lower Level

5:00pm-7:00pm: Welcome Reception (Open to All Attendees, Light Refreshments)

Remarks by Todd S. Talarico, President, APS Type 1 Foundation

Friday, July 7, 2023

Session Venue: Potomac Room (Lower Level)

8:00am-9:00am: Registration & Breakfast (*Venue: Lobby of Lower Level*)

9:00am-9:10am: Welcome Remarks

Todd S. Talarico, President, APS Type 1 Foundation

Dr. Jennifer Orange, Moderator & Board Member, APS Type 1 Foundation

9:10am-10:30am: Updates from the NIH Natural History Study and Clinical Trial

Dr. Michail Lionakis

10:30am-11:15am: Advances in the Management of Hypoparathyroidism

Dr. Karen Winer

11:15am-11:45am: Health Break

11:45am-12:30pm: Managing Type 1 Diabetes in APS Type 1

Dr. Mark Anderson and Dr. Alessandra Fierabracci

12:30pm-1:30pm: Networking Luncheon (*Venue: William Penn, Cabot & Clifton Rooms*)

1:30pm-2:15pm: Adrenal Insufficiency in APS Type 1 - Staying Well and Avoiding Crisis

Dr. Richard Auchus, Dr. Cheri Deal and Dr. Olle Kämpe

2:15pm-3:30pm: Managing Your Mental Health with APS Type 1

Dr. Maryland Pao

3:30pm-3:45pm: Health Break

3:45pm-4:00pm: Recent Developments Regarding Premature Ovarian Insufficiency

Dr. Olle Kämpe

4:00pm-5:00pm: Panel Discussion on the Future Work of the APS Type 1 Foundation

Todd S. Talarico, Robin Finch and Julia Richardson

Saturday, July 8, 2023

8:00am-9:00am: Breakfast (*Venue: William Penn, Cabot & Clifton Rooms*)

9:00am-11:00am: Concurrent Sessions

Concurrent Track 1: Physician/Scientist Roundtable (*Venue: Capitol Room, Lobby Level*)

Moderators: Dr. Jennifer Orange and Dr. Pushpa Rao

Concurrent Track 2: Patient/Family Track (*Venue: Potomac Room*)

(Attendees should feel free to move among these four circles)

1. Setting Yourself Up to Succeed in School

Discussion Leaders: Heather Talarico and Julia Richardson

2. Disability Supports and Strategies for Dealing with Insurance

Discussion Leaders: Todd Talarico and David Seyfert

3. Transitioning from Pediatric to Adult Care

Discussion Leaders: Gloria Uribe and Sherri Seyfert

4. Feeling Great and Looking Great! Living Well with Alopecia and Other

Differences (Featuring a special make-up artist from *Own Your Wonder*)

11:00am-11:10 am: Closing Remarks from Todd Talarico

Speaker Bios



Dr. Mark Anderson is a professor and physician scientist in the UCSF Diabetes Center and a recognized expert in the genetic underpinnings of autoimmune diseases and the control of immune tolerance. He helped establish a genetic mouse model of APS Type 1 to help understand how tolerance is disrupted in APS Type 1 patients.



Dr. Richard Auchus is a professor of pharmacology and internal medicine at University of Michigan. He is an expert in steroid biochemistry and adrenal diseases whose research includes disorders of the pituitary, adrenal, ovaries, and testes.



Dr. Cheri Deal is a pediatric endocrinologist and emeritus professor at the Université de Montréal, where she has practiced for over 30 years at the CHU Sainte Justine. Her major clinical and research interests focus around the GH-IGF axis and rare pediatric conditions, including rare syndromes and monogenic disorders. She has had the privilege of interacting with many patients and caregivers living with APS Type 1.



Dr. Alessandra Fierabracci has been Senior Scientist and Group Leader at Children's Hospital Bambino Gesù in Rome, Italy since 2001. Her research interests are related to the pathogenesis of autoimmune disorders with special reference to insulin-dependent diabetes mellitus (Type 1 diabetes) and autoimmune polyendocrine syndromes, including APS Type 1.

Speaker Bios



Dr. Olle Kämpe is professor and senior consultant in endocrinology at the Karolinska Institutet in Stockholm, Sweden. He is fellow of the Royal Swedish Academy of Sciences and vice chair of the Nobel Committee for the Prize in Physiology or Medicine.



Dr. Michail S. Lionakis is Chief of the Fungal Pathogenesis Section of the Laboratory of Clinical Immunology and Microbiology at the National Institute of Allergy and Infectious Diseases (NIAID), NIH. His IRB-approved APS Type-1/APECED clinical research protocol aims to understand the mechanisms of autoimmunity and fungal susceptibility and improve diagnostic and therapeutic strategies for patients.



Dr. Maryland Pao is Clinical Director and Deputy Scientific Director of the National Institute of Mental Health Intramural Research Program at the NIH. Dr. Pao helped develop the ASQ (Ask Suicide-Screening Questions), a validated suicide risk screening tool. Dr. Pao also helped to develop Voicing My CHOICES™, an advance care planning guide for adolescents and young adults. She is President of the Academy of Consultation Liaison Psychiatry.



Dr. Karen Winer is a senior medical officer at the National Institute of Child Health and Human Development (NICHD), NIH. During her fellowship years, she initiated the first controlled studies of parathyroid hormone (PTH) replacement therapy in the treatment of hypoparathyroidism in adults and children. Dr. Winer served on the editorial board of the Journal of Clinical Endocrinology and Metabolism for 8 years.

Foundation Leadership



TODD S. TALARICO

President, Chair of the Board and Co-Founder

Todd S. Talarico works in the pharmaceutical industry, focused on product and patient market access. Todd holds a BS from Bloomsburg University, PA, and a MS in Healthcare Management from the College of Saint Elizabeth, NJ. Since his daughter was diagnosed with APS Type 1 in 2006, Todd has worked tirelessly to develop the Foundation by raising awareness of the disease, working with the NIH and fundraising for research.



DR. JENNIFER ORANGE

Vice-President and Board Member

Jennifer Orange, the mother of a fabulous girl with APS Type 1, was the co-director of the First International Symposium on APS Type 1 in 2015 in Toronto and has developed the program for each symposium. She is passionate about advancing research in APS Type 1 and together with her family and friends she has raised over \$100,000 for APS Type 1 research. A law professor and human rights adjudicator with a doctorate in law from the University of Toronto, she has also served on the Board of Patients Canada and the Gerstein Crisis Centre.



SHERRI SEYFERT

Treasurer, Board Member and Co-Founder

Sherri Seyfert is the mother of two exceptional boys, Matthew (who has APS Type 1) and Jonathan. Sherri holds a BS from Stony Brook University and is a Licensed Physical Therapist. Through her persistent efforts, the Foundation obtained its 501(c)(3) nonprofit status in 2014. In 2017, the Seyfert family hosted the Second International Symposium on APS Type 1 at Stony Brook, NY.



ROBIN FINCH

Secretary and Board Member

Robin Finch is the mother of fifteen year-old, Samantha, who has APS Type 1. Robin fundraises for the Foundation through her family's "Slam Dunks for Sam" community basketball events. She spearheaded the creation of the APS Type 1 (APECED) Registry and hopes to develop a bio-bank. Robin practices real estate law at Greenberg Glusker in Los Angeles, California and holds a JD from UC Davis.



HEATHER T. TALARICO

Board Member and Co-Founder

Heather T. Talarico is a commercial claims specialist. Her involvement since the diagnosis of her daughter has included establishing the APS Type 1 Research Grant Program through NORD and coordinating fundraising events, which have supported seven research grant programs with NORD. Heather and Todd were the recipients of the NORD Distinguished Family Award in 2009.



DAVID SEYFERT

Board Member and Co-Founder

David Seyfert is the proud father of Matthew who was diagnosed with APS Type 1 at age 6. David holds masters degrees in Special Education and Orientation and Mobility and has worked with students with visual impairments for over 35 years. David and his wife, Sherri, ran the APS Type 1 Basket raffle to raise money for research for 10 years.



DR. PUSHPA RAO

Board Member

Dr. Pushpa Rao is the proud mom of three children, two daughters, Amrita and Neisha, and a son, Rajiv. Both Amrita and Neisha were diagnosed with APS Type 1 in 1992. It is to honor their lives and memory that she joined the board to help support research, outreach and patient support. Pushpa is a Diplomate of the American Board of Toxicology and recently retired as Head of Global Regulatory Affairs and Product Safety at a privately held company in New York.



DR. LAURA RIVARD

Board Member

Dr. Laura Rivard is a Teaching Professor and Outreach Coordinator for the Sciences at the University of San Diego. Her work in the Biology Department over the last 20 years has focused on genetics and related ethical issues. Her current efforts also include creating community engagement events and K-12 curricula to boost science literacy and interest and achieve more diversity in STEM fields. Dr. Rivard earned a B.S. in Biology from UCLA and a Ph.D. from UC San Diego based on her research in molecular neurobiology. She joined the Board in support of her remarkable niece, Samantha Finch.



JULIA RICHARDSON

Board Member

Julia Richardson is an adult with APS Type 1, wife to Roscoe Richardson, and mother of two children, Micah (14) and Hope (10) Richardson. She was diagnosed in 2002, at age 22, but manifested many disease components prior to diagnosis. Julia holds a master's degree in Medical Nutrition Therapy from The Ohio State University and is a Registered Dietitian Nutritionist. She has worked as a research coordinator and lecturer at The Ohio State University and is passionate about research and advocacy for those with rare disorders. Currently, she homeschools her children and manages her home and health.



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