Physicians / Researchers

Narendra Bagri, *Associate Professor, Department of Pediatrics & Medicine, All India Institute of Medical Sciences, New Delhi, India*

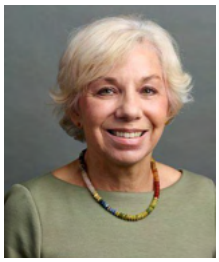
Narendra Bagri is an Associate Professor in the Division of Pediatric Rheumatology and Clinical Immunology in the Department of Pediatrics at the All India Institute of Medical Sciences (AIIMS) in New Delhi, India. His academic work includes more than 79 publications in PubMed-indexed journals (https://pubmed.ncbi.nlm.nih.gov/?term=narendra+bagri) and 20 chapters in various medical books.

Julie Barsalou, *CHU Sainte-Justine, Université de Montréal, Canada*

Dr. Julie Barsalou is a Pediatric Rheumatologist at CHU Sainte-Justine, where she has practiced since 2014. She completed her training in pediatric rheumatology, followed by additional training in clinical immunology and a fellowship dedicated to systemic lupus erythematosus and neonatal lupus. She also holds a Master's degree in Clinical Research, with a project focused on juvenile idiopathic arthritis. Her professional interests include the emerging role of cellular therapies in the management of autoimmune and autoinflammatory conditions.

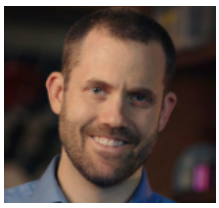
Claudia Bracaglia, *Senior Specialist (HLH/MAS reference), Division of Rheumatology, IRCCS Ospedale Pediatrico Bambino Gesù, Rome, Italy*

Dr. Claudia Bracaglia is a pediatric rheumatologist at Bambino Gesù Children's Hospital in Rome, combining clinical practice with translational research. She focuses on diagnosing and treating children with rheumatic diseases, including training at Boston Children's Hospital. Her research examines hyperinflammation, including sJIA/Still's, MAS and HLH, and their pathogenesis and biomarkers. Since 2021, she has led the European project on lung disease complicating sJIA/Still's disease. In 2022, she contributed to the international expert panels developing EULAR/PReS recommendations for Still's. She chairs the PReS MAS/sJIA Working Party.



Hermine I. Brunner, *Director, Division of Rheumatology, Professor, UC Department of Pediatrics, Cincinnati Children's Hospital Medical Center (CCHMC), Cincinnati, USA*

At Cincinnati Children's, Hermine Brunner, MD, MSc, MBA, conducts research on clinical trial endpoints, surrogate measures and biomarkers in pediatric rheumatic diseases, particularly lupus. She collaborates on clinical trials, drug development and biomarker discovery and validation, and has led multinational studies and developed outcome measures supporting drug approvals. As Scientific Director of the Pediatric Rheumatology Collaborative Study Group, she works with researchers at more than 90 academic centers across the U.S. and Canada to design and conduct trials of new treatments for children with rheumatic diseases.



Scott Canna, *Attending Physician, Immune Dysregulation & Rheumatology, The Children's Hospital of Philadelphia / Associate Professor of Pediatrics, University of Pennsylvania Perelman School of Medicine, Philadelphia, USA*

Scott Canna is an Attending Physician in Immune Dysregulation and Rheumatology at Children's Hospital of Philadelphia (CHOP) and an Associate Professor of Pediatrics at the University of Pennsylvania Perelman School of Medicine.

Sharat Chandra, *Member, Division of Bone Marrow Transplantation and Immune Deficiency, Assistant Professor, UC Department of Pediatrics, Cincinnati Children's Hospital Medical Center (CCHMC), Cincinnati, USA*

Sharat Chandra is an Associate Professor in the Division of Bone Marrow Transplantation and Immune Deficiency at Cincinnati Children's Hospital. His clinical practice focuses on transplantation for inborn errors of immunity, particularly SCID, Cartilage-Hair Hypoplasia, HLH and sJIA/MAS. His research examines chemotherapy pharmacokinetics and pharmacodynamics to improve conditioning regimens and transplant outcomes. He received the American Society of Bone Marrow Transplantation New Investigator Award.

Shan Chandrakasan, *Pediatric Hematologist/Oncologist, Children's Healthcare of Atlanta, Emory University, Atlanta, USA*

Shanmuganathan Chandrakasan, MD, is a professor in the Department of Pediatrics at Emory University School of Medicine and a member of the Cancer Immunology Research Program at Winship Cancer Institute of Emory University. He also leads one of the largest comprehensive immunohematology and immune dysregulation programs in the United States at Children's Healthcare of Atlanta.

Winn Chatham, *Professor and Division Chief of Clinical Immunology and Rheumatology, Department of Internal Medicine, University of Nevada, Las Vegas, USA*

Dr. Winn Chatham is Professor and Division Chief of Clinical Immunology and Rheumatology at UNLV's Kirk Kerkorian School of Medicine. He spent 37 years at UAB, serving as Clinical Director and directing its Lupus Clinic for 25 years. A Duke and Vanderbilt graduate, he completed residency at UNC Chapel Hill and fellowship at UAB. An ACR Master of Rheumatology, he received the ACR Clinician Scholar and Clinician Scholar-Educator Awards. His interests include lupus, immune deficiency-related autoimmunity and MAS.

Rebecca Coll, *Senior Lecturer in Immunobiology / Investigator, Wellcome-Wolfson Institute for Experimental Medicine, Queen's University Belfast, Northern Ireland*

Dr. Rebecca Coll is a Senior Lecturer in Immunobiology and Investigator at the Wellcome-Wolfson Institute for Experimental Medicine at Queen's University Belfast in Northern Ireland. Her research focuses on understanding the molecular mechanisms of inflammation and the role of inflammasomes in human health and disease. A particular area of her work is the development and characterization of small-molecule inhibitors of the NLRP3 inflammasome, including MCC950 and BAL0028. She is interested in studying inflammasome biology in human systems to advance understanding of inflammatory diseases and accelerate the development of new treatments.

Fabrizio de Benedetti, *Head, Division of Rheumatology, Ospedale Pediatrico Bambino Gesù, Rome, Italy*

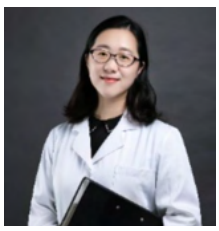
Fabrizio De Benedetti is a physician-scientist who earned his MD and PhD and completed training in pediatrics and pediatric rheumatology in Italy. After two years at the NIH, he worked at the Department of Pediatrics in Pavia before joining Bambino Gesù Children's Hospital in Rome in 2003, where he heads the Division of Pediatric Rheumatology, Laboratory of ImmunoRheumatology and Research Department of Immunology. His clinical and research interests focus on Still's disease and MAS, particularly their pathogenesis and biomarkers. Since his first publication on IL-6 in sJIA in 1991, he has designed and led pivotal international registration trials, serving as principal investigator for 12 phase II and III trials of innovative targeted therapies.

Luciana Martins de Carvalho, *Professor, Pediatric Rheumatology, Ribeirao Preto Medical School, University of São Paulo, Brazil*

Luciana Martins de Carvalho is a pediatric rheumatologist, professor and researcher at the Ribeirão Preto Medical School, University of São Paulo (FMRP-USP). She chairs the Pediatric Rheumatology Committee of the Brazilian Society of Rheumatology and is Vice-Chair of the corresponding committee of the São Paulo Society of Pediatrics. Her interests include systemic autoimmune and autoinflammatory diseases, rare conditions and immune dysregulation. She advances pediatric outcomes through clinical care, research and teaching.

Bruno Fautrel, *Bruno Fautrel, Professor of Rheumatology at Sorbonne University / Head of the Rheumatology Department at the Pitié Salpêtrière Hospital, Paris, France*

Bruno Fautrel is Professor of Rheumatology at Sorbonne University and Head of Rheumatology at Pitié-Salpêtrière Hospital. He completed his residency, Master's in Immunology at the Pasteur Institute, postdoctoral fellowship at McGill University and PhD at Nancy University. He contributed to cohort studies and led multicenter rheumatoid arthritis trials and a European multiomic project on autoinflammatory disease diagnosis. He is a member of the PEPITES team at INSERM Sorbonne University and co-director of the IMIDIATE clinical research network. His research focuses on Still's, and he co-led development of 2024 EULAR/PReS recommendations.



Qiong Fu, *Vice Director, Department of Rheumatology and Immunology / Chief Physician & Doctoral Supervisor, Renji Hospital, Shanghai Jiao Tong University School of Medicine, Shanghai, China*

Dr. Qiong Fu is Vice Director of the Department of Rheumatology and Immunology at Renji Hospital, Shanghai Jiao Tong University School of Medicine, where she is Chief Physician and Doctoral Supervisor. She completed a postdoctoral fellowship in rheumatology at UCLA and received the Shanghai Rising-Star Award. She holds leadership positions with the Shanghai Society of Rheumatology and the Chinese Medical Doctor Association, and has participated in AOSD clinical trials and published in leading rheumatology and immunology journals.

Alexei Grom, *Research Director, Division of Rheumatology, Cincinnati Children's Hospital Medical Center (CCHMC), Cincinnati, USA*

Dr. Alexei Grom's early work with pediatric rheumatology mentors shaped his clinical and research interests. During fellowship, the death of a patient from MAS prompted him to further study life-threatening complications of SJIA. His current research focuses on identifying risk factors and new therapeutic targets in MAS. His transnational studies identified IFN-γ as a therapeutic target in MAS, providing the rationale for the clinical trial. His research is funded by the NIH and Systemic JIA Foundation, and grants from Sobi, Novartis and AB2Bio.

Lauren Henderson, *Assistant Professor of Pediatrics, Harvard Medical School, Boston, USA*

Dr. Lauren Henderson is an Attending Physician in Rheumatology at Boston Children's Hospital and an Instructor in Pediatrics at Harvard Medical School. She oversees the daily operations of the New-onset JIA Registry and the Rheumatic Diseases of Childhood Biorepository at Boston Children's Hospital. In addition, she serves as the subcommittee chair for the CARRA (Childhood Arthritis and Rheumatology Research Alliance) federated biorepository that includes more than 60 pediatric rheumatology sites in the US and Canada. Her research focuses on the role of regulatory T cells in the pathogenesis of juvenile idiopathic arthritis.

Melissa Hines, *Associate Member (Professor), Division of Critical Care Medicine, St Jude Children's Hospital, Memphis, USA*

Dr. Hines is an Associate Member (Professor) in the Division of Critical Care Medicine at St. Jude Children's Research Hospital. She directs the Histiocytosis and Immune Dysregulation Treatment Team, which cares for patients with hyperinflammatory disorders, including hemophagocytic lymphohistiocytosis (HLH) and refractory cytokine release syndrome. Her research focuses on JAK inhibitors in hyperinflammatory syndromes, and she led a clinical trial evaluating ruxolitinib safety in pediatric HLH.

Swaminathan P. Iyer, *Professor / Center Medical Director, Department of Lymphoma/Myeloma, MD Anderson Cancer Center, Houston, USA*

Dr. Swaminathan P. Iyer is Professor in the Department of Lymphoma/Myeloma at The University of Texas MD Anderson Cancer Center. His clinical and research interests focus on lymphoma and the development of novel therapies. He completed his medical degree at Bangalore Medical College and hematology/oncology fellowship at the University of Miami.

Yuki Kimura, *Chief of the Pediatric Rheumatology Division, Joseph M. Sanzari Children's Hospital at Hackensack University Medical Center, New Jersey, USA*

Dr. Kimura is a clinical researcher and founding member of the Childhood Arthritis and Rheumatology Research Alliance (CARRA), a North American pediatric rheumatology research network. She has served as CARRA President, JIA Research Committee Chair and co-PI of the CARRA Registry. She led development of consensus treatment plans (CTPs) for systemic and polyarticular JIA and served as principal investigator of the STOP-JIA and FROST multicenter studies. STOP-JIA findings linked early biologic treatment to better disease activity over three years. She also co-leads a CARRA registry study on systemic JIA-associated lung disease.

Caifeng Li, *Professor, Chief Physician, Doctoral and Postdoctoral Supervisor, Department of Rheumatology and Immunology, Beijing Children's Hospital, Capital Medical University, Beijing, China*

Dr. Caifeng Li is Executive President of Beijing Children's Hospital Zhengzhou Hospital and holds leadership positions in several national and Beijing medical associations. She chairs pediatric rheumatology and immunology committees and serves as China's National Coordinator for the Pediatric Rheumatology International Trials Organization (PRINTO) and a member of the pediatric group of the Asia Pacific League of Associations for Rheumatology (APLAR). She is Deputy Editor-in-Chief of *International Journal of Rheumatic Diseases* and *Pediatric Rheumatology*, the official journals of APLAR and PReS, respectively.

Mariana Correia Marques, *Clinical Fellow, Translational Genetics and Genomics Section, NIH, Bethesda, USA*

Dr. Mariana Correia Marques completed medical school at the Universidade de Brasília (UnB) and her first pediatrics residency at the Universidade de São Paulo (USP), both in Brazil. She then completed a second pediatrics residency at the Boston Combined Residency Program, followed by pediatric rheumatology fellowship training at the University of Pittsburgh and Children's National Hospital/NIH. She received the American College of Rheumatology Distinguished Fellow Award in 2023. She is currently a Lawrence Shulman Scholar in Translational Research at the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), focusing on refractory forms of systemic juvenile idiopathic arthritis.

Rebecca Marsh, *Clinical Director, Primary Immune Deficiency and Dysregulation Program, Director, Diagnostic Immunology Laboratory, Cincinnati Children's Hospital Medical Center (CCHMC), Cincinnati, USA*

Rebecca is the clinical director of the Primary Immune Deficiency and Dysregulation Program and Director of Diagnostic Immunology Laboratory. As an immunologist and transplant physician, she treats patients with primary immune deficiencies and immune regulatory diseases. Through her research, she wants to improve allogeneic hematopoietic cell transplantation for patients with primary immunodeficiencies and is working to improve the treatment of patients with X-linked inhibitor of apoptosis (XIAP) deficiency.

Bella Mehta, *Rheumatologist, Hospital for Special Surgery/Will Cornell Medicine, New York, USA*

Dr. Bella Mehta specializes in the care of patients with rheumatic conditions including rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, systemic lupus erythematosus, osteoarthritis and has a particular interest in adult-onset Still's disease. Dr. Mehta is involved as an investigator in clinical studies focusing on disparities in rheumatologic diseases and has been the recipient of several awards for her research studies. Dr. Mehta's research reflects her commitment to achieving health equity, focusing on disparities in rheumatologic diseases Dr. Mehta leads studies to identify and build creative approaches using Big Data to improve diagnoses and patient outcomes. She is an active member of associations for medical professionals in rheumatology.

Francesca Minoia, *Pediatric Rheumatologist, IRCCS Ca 'Granda Foundation Maggiore Policlinico Hospital, Milan, Italy*

I'm a Pediatric Rheumatologist at Fondazione IRCCS Ca' Granda Ospedale Policlinico, Milan, Italy. I'm the current Secretary and Lead of Clinical Care of the MAS/sJIA Working Party of the Pediatric Rheumatology European Society (PRES). My main focus in research are hyperinflammatory syndromes, in particular MAS, secondary HLH and Still's disease. In the last years, I have led the METAPHOR project to capture the real-life practices and challenges in the treatment of Still's disease and macrophage activation syndrome and the PReS/CARRA collaborative initiative to define a standardized core dataset for Still's disease.

Michael Ombrello, *Investigator Chief, Translational Genetics and Genomics, NIH, Bethesda, USA*

Dr. Michael Ombrello is an adult and pediatric rheumatologist and Tenure-Track Investigator at NIAMS. He earned his undergraduate and medical degrees from Saint Louis University, became an inaugural NIAMS Henry Metzger Scholar in Translational Research and completed postdoctoral training at the National Human Genome Research Institute. His research focuses on the genetics of rare inflammatory diseases, including defining the genetic architecture of Still's disease through the INCHARGE Consortium. He identified the first disease-causing PLCG2 mutations in humans and continues to study related immune-mediated diseases.

Daniela Piotto, *Pediatric Rheumatologist / Professor, Federal University of São Paulo, Brazil*

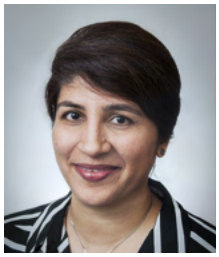
Daniela Piotto, MD, PhD, is a pediatric rheumatologist and affiliated professor at the Federal University of São Paulo (UNIFESP), Brazil. She has over 20 years of clinical and academic experience in pediatric autoimmune and autoinflammatory diseases, immune dysregulation and rare rheumatic conditions, including systemic juvenile idiopathic arthritis and macrophage activation syndrome. Her clinical and research interests include high-frequency skin and musculoskeletal ultrasound and nailfold videocapillaroscopy to assess disease activity and monitor treatment response. She is also involved in clinical care, research and medical education.

Athimalaipet V. Ramanan, *Pediatric Rheumatologist / Head of Research, Bristol Royal Hospital for Children, United Kingdom*

Professor Ramanan is a consultant pediatric rheumatologist at the Bristol Royal Hospital for Children and Head of research at the Bristol Royal Hospital for Children. He was elected Fellow of Academy of Medical Sciences UK in 2023. He was awarded the British Society of Rheumatology's Innovation in Clinical Practice Award in 2010. He was awarded the University of Bristol Vice Chancellor's Health Impact award in 2017 and RCP/NIHR CRN Award in 2018. Professor Ramanan has published over 300 articles. He is Co-Editor of Rheumatology and one of the Editors of 5 th Edition of Oxford Textbook of Rheumatology.

Grant Schulert, *Assistant Professor of Pediatrics, Cincinnati Children's Hospital Medical Center (CCHMC), Cincinnati, USA*

Dr. Grant Schulert is a pediatric rheumatologist and researcher specializing in autoinflammatory disorders, juvenile idiopathic arthritis (JIA), systemic JIA, and its complications, including macrophage activation syndrome and lung disease. His research focuses on the dysregulation of innate immunity in inflammatory diseases, particularly severe sJIA complications. With his colleagues, he investigates the causes of these complications, approaches to controlling hyperinflammation, and the use of novel biomarkers and genomics to guide treatment.



Susan Shenoi, *Professor of Pediatric Rheumatology, Seattle Children's Hospital, Washington, USA*

Susan Shenoi is a Professor of Pediatric Rheumatology and Adjunct Professor of Epidemiology at the University of Washington. At Seattle Children's Hospital, she directs the Cure JM-SCH Juvenile Myositis Center of Excellence and serves as Medical Director of Medical Affairs and Medical Staff President. Her research focuses on epidemiology, environmental factors and outcomes in juvenile idiopathic arthritis, particularly systemic JIA, as well as collaborative clinical research in juvenile myositis. She is an active member of CARRA and PRCSG and serves as Senior Editor of *Pediatric Rheumatology*. She is passionate about raising awareness and improving outcomes in pediatric rheumatic diseases.

Cory Stingl, *Pediatric Rheumatologist, Corewell Health / Michigan State University, Grand Rapids, USA*

Dr. Stingl was diagnosed with sJIA at age 4. He is also a pediatric rheumatologist in Grand Rapids, MI (West Michigan) soon to be relocating to the Medical College of Wisconsin in Milwaukee, WI. Dr. Stingl's research interest is in finding new treatments for sJIA.

Matteo Trevisan, *Physician, Division of Rheumatology, IRCCS Children Hospital Bambino Gesù, Rome, Italy*

Matteo is a physician and PhD student in the Division of Rheumatology at IRCCS Bambino Gesù Children's Hospital in Rome. His clinical and research work focuses on Still's disease, hemophagocytic lymphohistiocytosis (HLH) and macrophage activation syndrome (MAS), with a particular interest in prognostic biomarkers in Still's disease. His group recently published data showing that IL-18 levels at disease onset predict a chronic disease course, disease activity and the risk of future MAS episodes.

Bas Vastert, *Pediatric rheumatologist-immunologist and Professor of Translational Pediatric Rheumatology, University Medical Center Utrecht, Netherlands*

Dr. Bas Vastert is a pediatric rheumatologist-immunologist and Head of Pediatric Rheumatology and Immunology at Wilhelmina Children's Hospital in Utrecht. He co-leads a translational research group at Utrecht's Center for Translational Immunology, focusing on Still's disease, systemic inflammation and new treatments for Still's and JIA. He leads the Dutch multicenter ESTIS trial, investigating a biomarker-driven approach to discontinuing rIL-1RA therapy in sJIA, and is a principal investigator of the binational UCAN CAN DU cohort study developing personalized JIA treatments. He also leads its Dutch implementation project, UCAN JUMP, and co-leads the THRILL trial investigating anakinra for pediatric oncology patients with sepsis and hyperinflammation.

Holly Wobma, *Physician-Scientist, Pediatric Rheumatology, Boston Children's Hospital, Boston, USA*

Holly Wobma, MD, PhD, is a physician-scientist in pediatric rheumatology at Boston Children's Hospital. She completed her MD/PhD training at Columbia University, earning her PhD in Biomedical Engineering, followed by pediatric residency and fellowships in pediatric rheumatology and stem cell transplantation/cellular therapy at Boston Children's Hospital. Her research focuses on developing cellular therapeutic strategies to achieve durable immune tolerance in patients with autoimmune diseases.

Patients & Families

Vincent Del Gaizo, *USA*

Vincent has been active in pediatric rheumatology since 2001, when his then 15-month-old son was diagnosed with SJIA. He is Director of Partnerships & Patient Engagement at Childhood Arthritis & Rheumatology Research Alliance (CARRA) and a past member of the National Institute of Arthritis and Musculoskeletal and Skin Diseases Advisory Council. He served as Co-Chair of the Patient-Centered Outcomes Research Institute (PCORI) Rare Disease Advisory Panel from 2015–2018. Vincent brings patient perspectives to research projects, including clinical trials and comparative effectiveness studies, and mentors patients and caregivers as research partners.

Brittney Franklin, *USA*

Brittney Franklin is Director of Patient Advocacy at Lundbeck, leading U.S. advocacy strategy for its Multiple System Atrophy program. Her path into industry began with her daughter Aspen's HLH diagnosis in 2013. After a failed transplant, genetic testing revealed XIAP deficiency. Aspen participated in emapalumab and MAS825 clinical trials before receiving a second bone marrow transplant in April 2026. Brittney is committed to bringing patient and family experiences into treatment development and advocacy.

Janine Kelly, *Denmark*

Janine is the mother of Kobi, who was diagnosed with sJIA at 2½ in 2024. His course has been complicated by 3 severe episodes of MAS, recurrent infections and significant neurological complications requiring intensive care. His treatments included high-dose steroids, IVIG, anakinra, tocilizumab, sarilumab and canakinumab. He is now on tofacitinib, anakinra, methotrexate and prednisolone, with ongoing neurological rehabilitation and recovery.

Marta Silva Mendes, *Belgium*

Marta Silva Mendes is a manager at the European Commission in Brussels, Belgium, with over 20 years of experience in leadership, human resources, and organisational development. She is also the mother of four boys, one of whom lives with Still's disease. Her son's illness has led her on a journey to understand a complex and unpredictable condition, navigate medical uncertainty, and explore treatment options. This experience has given her a personal understanding of the challenges families face with rare inflammatory diseases and the importance of research, communication, and collaboration between healthcare professionals and families.

Robert Moates, *USA*

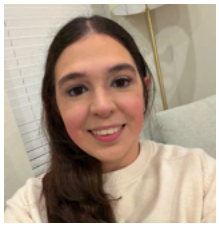
Rob is the father of Ellanora, who was diagnosed with SJIA in spring 2022. Her family has worked with medical teams at Johns Hopkins All Children's in St. Petersburg and Cincinnati Children's Hospital. Her treatment has progressed from DMARDs to biologics and now a combination of biologics, alongside oral steroids since diagnosis. Rob has worked in the Florida Legislature and U.S. Congress and currently teaches economics for Florida Virtual School. His wife, Kara, is an oncology nurse navigator.

Alok Patro, *India*

Alok Patro was diagnosed with Still's disease at age 18 and achieved remission after treatment, remaining symptom-free for approximately 14 years. Following a relapse in October 2022, he was initially misdiagnosed with ankylosing spondylitis. A second opinion at CMC Vellore confirmed a bimodal pattern of Still's disease, and he began Actemra, methotrexate and steroids in July 2023. Despite an initial response, Actemra's effectiveness waned, and he continues to experience flares.

Jodi and Miles Plont, *USA*

Advocate, caregiver, and proud parent to a daughter living with sJIA. Dedicated to raising awareness, supporting the rare disease community, and fighting for inclusion & better resources for children like Lucy. She was diagnosed in 2023, and we still have not found a medication to put her arthritis into remission. After three years of steroid use to manage this disease, Lucy has multiple complications on top of sJIA that make life tough, but her spirit and light continue to shine brightly.



Sarah Prado, *Brazil*

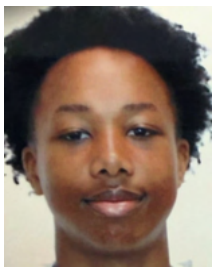
Sarah is from Brazil and lives with Still's disease. Diagnosed in April 2022 at age 28, she initially managed her condition with steroids but switched to methotrexate after developing acute osteonecrosis in both knees. After methotrexate proved unsuccessful, she began Actemra (tocilizumab) in December 2022, which has kept her disease well controlled, with minimal impact on daily life beyond medication side effects. She volunteers with AiArthritis on initiatives including Still's Disease Awareness Day and World AiArthritis Day, and moderates a patient group in Brazil.

Robyn Rivera, *USA*

Robyn is the mother of Madyson, who was diagnosed with HLH in 2020 and subsequently with SJIA. After years of refractory disease, MAS and ILD, Madyson underwent a matched unrelated donor bone marrow transplant in April 2024. Her treatment has included Gamifant, anakinra and ruxolitinib. She continues to manage post-transplant inflammation but is back at school and doing well academically.

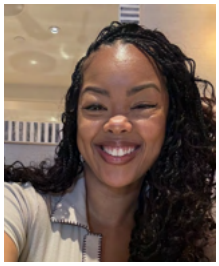
Zuly Rivera, *USA*

Zuly is the mother of Sabreen, diagnosed with SJIA at age 4, with severe liver involvement and MAS confirmed by biopsy. After anaphylactic reactions to IV steroids and other treatment challenges, she began Gamifant in January 2020, which normalized her liver enzymes and substantially lowered IL-18. She continues monthly Gamifant with Xeljanz and has been doing well, with her last major flare in June 2025. Her family is weighing the long-term treatment approach and whether BMT may be appropriate.



Channing Russell, *USA*

Candi's son, Channing is a STEM student, an athlete, and a kid with big dreams and a love for science and space. After nearly a year and a half of searching for answers, he was diagnosed with sJIA and MAS in December 2025. Since then, his life has included hospital stays, painful flares, and time away from the sports he loves. Watching him go through this has been heartbreaking for his mom, but she is so proud of him. They are still working toward lasting stability while learning, advocating, and getting involved in research. Their hope is for Channing to get back to doing what he loves and for more families to find answers and support.



Candi Tambwe, *USA*

I'm a mother of three and a passionate advocate for my son, whose battle with sJIA and MAS has forever changed our lives. From life-threatening hospitalizations and failed treatments to insurance battles and relentless advocacy for appropriate care, our journey has demanded strength and resilience. Watching my once active, athletic son struggle with pain, debilitating flares, and the loss of activities he loves has fueled my determination to make a difference. I'm committed to raising awareness, supporting families, challenging barriers to care, and advancing research. I hope to collaborate with medical professionals and use our experiences to help improve diagnosis, treatment options, and outcomes for the sJIA community.

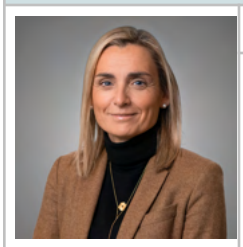
Karrah Washington, *USA*

Karrah is the mother of Brayton, who was diagnosed with sJIA and MAS in 2025. His treatment has included high-dose steroids, anakinra, IVIG and Jakafi (ruxolitinib), with anakinra and steroids later tapered off. He is currently on Jakafi and has returned to one of his favorite activities, dirt bike racing.

Patient, *China*

I am a 22-year-old combined Master's-PhD student in economics in China. I was diagnosed with sJIA at age 10 in 2014. After achieving remission and discontinuing treatment in 2016, I developed sacroiliac joint pain in 2021 and have since undergone several treatment changes, most recently returning to Cosentyx, which has provided complete relief from pain. In 2025, I helped start a sJIA patient group in China. I describe myself as "more a volunteer than a patient" and am committed to supporting others living with sJIA.

Pharma



Lydia Abad-Franch, *Chief Medical Officer / Head of R&D and Medical Affairs, Sobi, Switzerland*

Dr. Lydia Abad-Franch has served as Chief Medical Officer and Head of R&D and Medical Affairs at Sobi since 2020. Previously, she held medical affairs roles at Shire/Takeda and served as Associate Medical Director for Baxter EMEA and Global Medical Advisor for Haemophilia at Novo Nordisk. Her research includes congenital bleeding disorders at University Hospital La Fe and rheumatology at University Hospital Dr. Peset in Spain. She earned her medical degree from the University of Valencia, completed PhD coursework and received recognition for research. She is board-certified in family medicine and holds an MBA from Carlos III University of Madrid.

Reddy Belum, *Clinical Research Medical Director, Novartis, USA*

Dr. Reddy Belum is a Clinical Research Medical Director supporting rheumatology programs at Novartis.

Heather Bodenstab, *Associate Medical Director, Kineret, Sobi, USA*

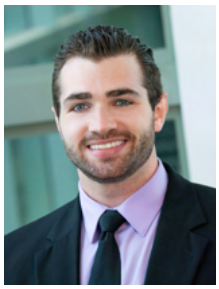
Heather Bodenstab is Associate Medical Director for Kineret at Sobi. Before joining the pharmaceutical industry, she spent 14 years caring for neonatal patients at Children's Hospital of Philadelphia as a clinical pharmacist.

Erin Bogren, *Director Thought Leader Liaison, Sobi, USA*

Erin Bogren is Director of Thought Leader Liaison at Sobi. She has more than 20 years of experience in the pharmaceutical and biotechnology industries, including leadership roles in health systems and regional business management at Sobi, Takeda, Shire and Novartis.

Hung-Kai Kevin Chen, *Founder, Chairman, Chief Executive Officer & Chief Medical Officer, Elixiron Immunotherapeutics, USA*

Dr. Hung-Kai Kevin Chen is a physician-scientist, biotech entrepreneur and pharmaceutical executive with over 25 years of experience in biomedical research and drug development. He is Founder, Chairman, CEO and Chief Medical Officer of Elixiron Immunotherapeutics, advancing two precision immunotherapies into Phase II trials for Alzheimer's and vitiligo. He also founded NeuroVantix Therapeutics. His achievements include two Alzheimer's Association Part the Cloud Awards (2020, 2022) and Taiwan's National Innovation Award (2020). Previously, he held senior roles at GSK, Gladstone Institutes, Development Center for Biotechnology and Eusol Biotech. He completed postdoctoral training at Baylor College of Medicine and HHMI, holds MD and PhD degrees from National Yang-Ming University, and has published in *Cell*, *Nature Medicine* and *Cancer Discovery*.



Nicholas Ciaramitaro, *Patient Engagement Lead in Clinical Development, Sanofi, USA*

Nicholas Ciaramitaro is a Patient Engagement Lead in Clinical Development at Sanofi, where he brings the patient and caregiver voice into how trials are designed and run. He collaborates with patient advocacy organizations across immunology, rare disease, respiratory, and oncology to review protocols and patient-facing materials, pressure-test study burden and risk tolerance with families, and translate those insights into more feasible, patient-centric trials. He holds a PharmD from Wayne State University and has been at Sanofi in this role for over 2 years. Nick comes to NextGen to listen: to learn from patients, caregivers, clinicians, and regulators what living with sJIA looks like, how families weigh trial participation, and where gaps in care are widest.

Kevin Connors, *Development Scientific Director, Sanofi, USA*

Kevin Connors, PharmD, is a Development Scientific Director at Sanofi supporting clinical research in the Immunology Division. His career has spanned across community, academic, institutional and industry venues providing a broad perspective on the journey from scientific discovery to patient care. Kevin is passionate about advancing meaningful therapies and values the insights that patients, caregivers, and advocacy organizations bring to research. He looks forward to learning from the NextGen community and strengthening collaborations that help improve outcomes for patients and families.

Kim-Hien Dao, *Chief Medical Officer, Electra Therapeutics, USA*

Dr. Kim-Hien has served as Chief Medical Officer of Electra Therapeutics since May 2024, and previously served as Vice President, Head of Clinical Development from April 2023 to May 2024. She is a clinician scientist with more than 15 years of research experience in academia and biotech. Prior to joining Electra, Kim-Hien was Senior and Executive Medical Director of Clinical Development at Astex Pharmaceuticals from November 2019 to March 2023, where she worked on four drug programs for solid tumors and hematological malignancies. She is an actively practicing hematologist in a volunteer capacity.

Elena Burillo Ipiens, *Global Medical Affairs Director in Immunology, Sobi, Spain*

I'm Elena Burillo, Global Medical Affairs Director in Immunology at Sobi, a company focused on rare diseases. I lead medical strategy in rare inflammatory conditions, including Still's disease, MAS and HLH. I'm joining NextGen to listen and learn, and to help make sure research answers the questions that matter most to people living with Still's disease.

Brian Jamieson, *Therapeutic Area Head for Immunology, Sobi, USA*

As Therapeutic Area Head for Immunology at Sobi, Brian oversees development and medical affairs for anakinra and emapalumab.

Michelle Kosich, *Senior Medical Director, Immunology, Sobi, USA*

I am a US Medical Affairs professional at Sobi, where I support the Gamifant program with a focus on rare immunologic diseases such as HLH and MAS. I bring many years of experience on U.S. medical teams and as a clinical pharmacist, and I am passionate about bridging clinical science and real-world patient care. My work centers on helping physicians, patients, and caregivers navigate complex, hard-to-diagnose conditions, with a particular interest in immunology and the role of hyperinflammation in rare disease. I am glad to be part of a community working to shorten the path to diagnosis and expand treatment options for families.

Olivia Maurel, *Head of Global Regulatory Affairs & Medical Writing, Sobi, Switzerland*

Olivia Maurel, Pharm.D., is Head of Global Regulatory Affairs & Medical Writing at Sobi, where she leads a global organization supporting a rare disease portfolio across immunology, rheumatology, oncology, nephrology, hematology and specialty care. With more than 30 years of international experience in regulatory affairs, pharmacovigilance and drug development, she has led global regulatory strategies from early development through lifecycle management and supported major approvals across the US, Europe, Japan and China. Her experience includes biologics, rare diseases and immune-mediated conditions, with a focus on advancing scientifically robust, patient-centered development programs.

Dr. Isaac Meng, *Chief Medical Officer, TJ Biopharma, China*

Dr. Yuan (Isaac) Meng is CMO of TJ Bio, where he leads clinical development strategy for the company's pipeline, driving team development and operational excellence across immunology, inflammation and immuno-oncology. With 25 years of industry experience, he served as Cross-Sector Safety Lead at J&J in China. At Pfizer, he focused on oncology products, serving as Global Safety Lead and Chair of the Safety Management Team. He began his industry career at Eli Lilly, Wyeth and BMS. Before entering the pharmaceutical industry, he practiced and taught neurology at Ruijin Hospital in Shanghai. He is a graduate of Shanghai Medical University and serves on the ICH E2D(R1) Global Expert Working Group and ICH MedDRA Steering Committee.

Adam Narloch, *Head of Market Development, Electra Therapeutics, USA*

Adam Narloch is Head of Market Development at Electra Therapeutics, where he focuses on secondary hemophagocytic lymphohistiocytosis (sHLH), disease awareness and engagement with clinicians and patient communities. He brings nearly a decade of experience in HLH and a deep commitment to affected patients and families. His relationships with the HLH community have given this work personal meaning and fueled his passion for improving lives. Adam looks forward to strengthening connections with the Still's disease, sJIA and MAS community, listening to families' experiences and supporting meaningful progress. He joins NextGen committed to keeping patients and families at the heart of his work.

Shauna Pennington, *Rare Disease Marketing Specialist, Sobi, USA*

Shauna Pennington works in Rare Disease Marketing at Sobi. She is passionate about elevating the voices of patients and caregivers, ensuring their experiences and perspectives help shape meaningful education, engagement and support.

Eduardo Schiffrin, *Chief Medical Officer, AB2Bio SA, Switzerland*

Dr. Eduardo Schiffrin is a physician trained in human pathology and immunology, with experience in research, pediatric gastroenterology and clinical development. He earned his medical degree and doctorate from the Universidad Nacional de La Plata in Argentina and completed a fellowship in Pediatric Gastroenterology and Nutrition at Harvard University. At Nestlé, he led the Immunology group and held senior medical leadership roles. He is currently Chief Medical Officer at AB2 Bio in Lausanne, Switzerland, leading clinical development and medical strategy for IL-18 pathway inhibition in rare monogenic hyperinflammatory diseases.

Kimberly Serota, *Director of Advocacy and External Relations, Sobi, USA*

Kimberly Serota is Director of Advocacy and External Relations at Sobi, where she leads advocacy strategy, external engagement, and policy positioning in rare disease and specialty care. With more than 10 years of advocacy experience, she builds partnerships that elevate patient perspectives and translate shared priorities into policy impact. Kimberly has cultivated relationships with patient advocacy organizations, industry groups, and medical societies, launched two national cancer-focused coalitions engaging 40 organizations, and advocated for patients through federal lobbying and engagement on healthcare legislation and regulatory policy. She holds a Master of Social Work in Management and Community Organization from the University of Maryland, Baltimore.

Mona Trivedi, *Global Program Clinical Head, Novartis, USA*

A rheumatologist by training and in the industry for over 12 years in clinical development of various diseases in rheumatology/dermatology/GI areas. Now at Novartis overseeing clinical development of MAS825. Still's disease (including peds and adults) is one of the diseases for which MAS825 is being developed. I look forward to learning and meeting colleagues at this conference!

Guliang Xia, *Senior Vice President, Changchun GeneScience Pharmaceutical (GenSci), China*

Dr. Guliang Xia holds a PhD in Immunology from the University of Leuven (KU Leuven) in Belgium and is Senior Vice President at Changchun GeneScience Pharmaceutical (GenSci), where he leads the Center for Immunobiology and oversees research in endocrinology and metabolism, neuropsychiatry and small molecules. With nearly 30 years of experience in medicine, immunology and drug development, he has led nearly 100 drug discovery projects targeting immune-mediated inflammatory diseases, several advancing to clinical trials, including Phase III. His career includes research and academic appointments at Ohio State University, the Medical College of Wisconsin and Northwestern University, as well as pharmaceutical leadership roles at Astellas, Novo Nordisk, Synthetic Genomics, Roche and Takeda. He has authored more than 50 scientific papers and patents and brings extensive experience in drug discovery, external partnerships and licensing.

FDA

Tresa Ambooken

Tresa Ambooken, MD, MBA, is a Medical Officer in the Division of Rheumatology and Transplant Medicine at the Food and Drug Administration (FDA), where she has been serving as a clinical reviewer since 2024.

Kimi Chan

Carrie Diamond

Brian Dizon

I am a medical officer at FDA and an adult and pediatric rheumatologist. I am interested in immunology, rheumatology, and rare disease.

Emily Gotschlich

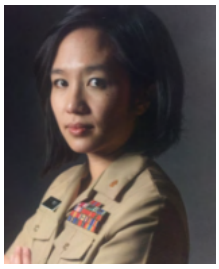
Dr. Emily C. Gotschlich is a clinical reviewer in the Division of Rheumatology and Transplant Medicine (DRTM) at the U.S. Food and Drug Administration (FDA). She earned her B.S. from Duke University and M.D. from New York University, completed pediatric residency at Mount Sinai and pediatric rheumatology fellowship at Children's National Hospital and the National Institutes of Health (NIH). Since joining the FDA in 2021, she has reviewed multiple rheumatology products, with a focus on pediatric drug development. She continues to see pediatric rheumatology patients weekly at Children's National Hospital.

Elizabeth Hart

Dr. Elizabeth Hart serves as Acting Associate Director for Rare Disease within FDA's Center for Drug Evaluation and Research (CDER). She leads CDER's multi-disciplinary Rare Diseases Team and is also the program manager for CDER's Accelerating Rare Disease Cures Program. She completed her medical training at the University of Pennsylvania Perelman School of Medicine, a residency in pediatrics at Rainbow Babies and Children's Hospital and a fellowship in pediatric endocrinology at Boston Children's Hospital. Before joining FDA in 2014, she delivered direct patient care and conducted clinical and translational research in rare diseases.

Raj Nair

Dr. Raj Nair is Division Director of Rheumatology and Transplant Medicine (DRTM) at the FDA. He completed a research fellowship at the University of Alabama at Birmingham under Dr. Kenneth Saag, followed by a clinical rheumatology fellowship at the University of North Carolina at Chapel Hill. He later served as an attending physician at Washington Hospital Center and earned musculoskeletal ultrasound certification through the American College of Rheumatology. He joined the FDA full-time in 2013 and became a clinical team leader in 2021. He has spoken at national American College of Rheumatology meetings and conferences on regulatory policy, patient perspectives and specific diseases.



Suzette Peng

Dr. Suzette Peng is a board-certified internist and rheumatologist. She joined the FDA in 2012 as a medical officer and is an acting team leader in what is now the Division of Rheumatology and Transplant Medicine in the Center of Drug Evaluation and Research. She completed an internal medicine residency and rheumatology fellowship at Walter Reed Army Medical Center in 2005 and 2009, respectively. She currently sees patients in the rheumatology clinic at AT Augusta Military Medical Center. She was an officer in the US Army and is now a Captain in the US Public Health Service with whom she has served in multiple national and global responses, including the Ebola crisis in 2014, Hurricane Maria in 2017, and the COVID-19 public health emergency in 2020.

Juwaria Waheed

Dr. Juwaria Waheed is a board-certified adult rheumatologist who earned her medical degree from the University of Maryland School of Medicine and completed her rheumatology fellowship at Johns Hopkins University School of Medicine. She joined the FDA's Office of New Drugs as a Clinical Reviewer in the Division of Rheumatology and Transplant Medicine before transitioning to the Office of Therapeutic Biologics and Biosimilars. She views the biosimilars program as an important opportunity to advance public health by expanding patient access to biologic medications and driving scientific innovation.

Jeong Min Yu

Dr. Jeong Min Yu is a board-certified rheumatologist and internist and Medical Officer at the FDA, serving as a Clinical Reviewer in the Division of Rheumatology and Transplant Medicine. Her work spans drug development, including clinical trial and marketing application reviews and postmarketing safety evaluations, focusing on treatment safety, efficacy and benefit-risk assessment. Before joining the FDA, she completed her rheumatology fellowship at Hospital for Special Surgery, where she researched patient-reported outcomes in systemic sclerosis. Her interests include immunology, innovative therapeutics and patient-centered drug development.

Systemic JIA Foundation

Jonathan Boutelle

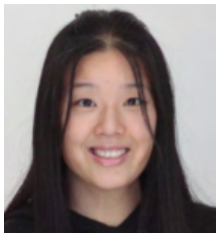
Jon Boutelle is co-founder and Board Member of the Systemic JIA Foundation and the father of a child with Still's disease and MAS. A software engineer and entrepreneur, Jon studied Computer Science and Psychology at Brown University. He began his career as a software engineer before co-founding a user experience consulting firm and later SlideShare, where he served as Chief Technology Officer. SlideShare grew into a global platform for sharing knowledge and was acquired by LinkedIn in 2012. Jon has also been an active angel investor in technology startups, and posts finance videos on Instagram and TikTok at @letyourwinnersrun. At the Systemic JIA Foundation, he contributes his expertise in technology, organizational strategy, and nonprofit operations.

Rashmi Sinha

Rashmi Sinha is co-founder and Executive Director of the Systemic JIA Foundation and the mother of a child with Still's disease and MAS. She holds a PhD in cognitive neuropsychology from Brown University and completed postdoctoral research in cognitive neuroscience at UC Berkeley, where she also taught in the information sciences program. She later turned to entrepreneurship, co-founding a user experience consulting firm and then SlideShare, a knowledge-sharing platform acquired by LinkedIn. At the Systemic JIA Foundation, she draws on her scientific and entrepreneurial background and personal experience to connect patients, clinicians, and researchers, accelerate research, and advance treatments for Still's disease.

Anna Carlson

Anna lives in Saratoga Springs, Utah with her husband and three children. She is a paralegal working in the cyber security industry. Her daughter, Sophia (11), was diagnosed with SJIA at 14 months, ILD at 19 months and PAP just before she turned three. Sophia's disease has been relatively controlled with her current medications, but struggles with lung disease progression, including lung hemorrhages. Sophia has been unable to taper off of steroids and has been on oral steroids for 10 years. Despite her many surgical procedures, hospitalizations and daily medications, she is a very happy, social and quirky little girl who loves animals.



Hanyi Chrisman

Hanyi Chrisman has a BS in EECS and a MS in biomedical engineering. She is a board member and technical lead at a medical nonprofit in California. Along with her husband, Hanyi homeschools their three sons, two of whom have medical needs. Their youngest son developed SJIA in 2023 with reliably quotidian fevers, all-body rash, and debilitating arthritis. After difficulties obtaining a diagnosis and facing increasing eosinophilia, he was transferred to Cincinnati Children's Hospital. Now, he is in medicated remission on anakira and has started weaning. Hanyi has been volunteering with Systemic JIA Foundation since 2024 to assist with technical needs.

Leah Bush

Leah Bush is a Community Health Worker and director of a nonprofit focused on youth mental health and suicide prevention in rural Appalachia. She lives in Rosman, NC, with her husband and three children. Her 15-year-old son, Ezra, was diagnosed with SJIA around his first birthday and has since faced refractory disease, complex combination treatments, multiple drug hypersensitivities, and complications from long-term steroid use. Despite these challenges, Ezra enjoys culinary classes, gaming, ROTC and Young Life. Leah has also helped build an international online community of more than 2,900 caregivers of children with Still's disease.

Luciana Pereira

Luciana is a chemical engineer with experience in the chemical and pharmaceutical industries. Based in Brazil, she spent 11 years living in North America and Europe, gaining a multicultural perspective. Her daughter's journey with severe SJIA and MAS, leading to a bone marrow transplant and remission in 2018, inspired her patient advocacy work. She supports the SJIA Foundation by connecting families across Europe and South America, helping them explore treatment options, and contributing to SJIA research.