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Mother and Rare Disease Advocate Teams Up with Leading Pediatric Psychologist to Pen First-of-its-Kind Book for Parents

Book aimed at equipping parents with the knowledge and skills to successfully support their children through medical challenges, and specifically with medical trauma and anxiety

NASHVILLE – (July 16, 2021) Being heralded as a 'groundbreaking guide for families facing medical challenges,' the new book, *Afraid of the Doctor: Every Parent's Guide to Preventing and Managing Medical Trauma*, is the product of two mothers who have both experienced – and become experts on – childhood medical trauma in vastly different ways.

Endorsed by the Child Neurology Foundation, *Afraid of the Doctor* is the first book written for parents with the primary goal of equipping them with the knowledge and skills to support their children through medical challenges, and specifically with medical trauma and anxiety. Medical trauma describes the emotional and physical responses to pain, injury, serious illness, medical procedures, and frightening treatment experiences and is often under-recognized and overlooked in the healthcare system.

Melissa Hogan, J.D., is the mother of three, whose youngest son was diagnosed with Hunter syndrome as a toddler. She has spent the last decade navigating difficult medical appointments, researching, blogging and becoming an expert on rare diseases such as the one affecting her son. In 2014 she left her career as a health care attorney and was among a group of parents who founded <u>Project Alive</u>, the leading non-profit focused on supporting treatments, cures, and advocacy for Hunter syndrome.

Meghan Marsac, Ph.D., is a pediatric psychologist and a tenured Associate Professor at the University of Kentucky and Kentucky Children's Hospital. She is a leader in the field of pediatric medical trauma, having published more than 60 academic articles on this topic and founding the <u>Cellie Coping Company</u> to provide evidence-based tools for emotional support for children with medical conditions. Her primary professional goal is to improve the experience of living with medical conditions for children and families.

Medical trauma and experiences in healthcare can profoundly affect a child's response and willingness to even go to the doctor. "When my child was first diagnosed, I found very few tools and no books for parents. I felt very alone," Hogan said. "This is the book I wish I'd had. It has the information and the tools I needed to help my child. I was so excited to reach out to Meghan and bring together the perspectives of both a parent and a psychologist to help families."

When parents understand medical trauma and learn strategies to reduce and even prevent it, they become empowered to better care for their child's emotional and physical health. The book could not

be timelier considering the COVID-19 pandemic and the medical fears it is causing in both children and parents. After more than a year of lockdowns, virtual learning, mask wearing and social distancing, some children may have a traumatic experience adjusting back to "normal."

"We wanted to be able to give the kids and the families I work with every day the resources to help them manage their medical experience and walk their physical health journey and their mental health journey together," Marsac said. "One of my primary goals is to make medical care better for kids and families, so that's why we came together and wrote this book."

Early praise for the book has come from medical experts who tout the need for the book including the Chief Medical Officer at WebMD, the pediatrics chair at Monroe Carrell Jr. Children's Hospital at Vanderbilt, the director of the Center for Pediatric Traumatic Stress at Children's Hospital of Philadelphia, the genetic counselor for the Rare Disease Program at Cincinnati Children's Hospital Medical Center and others.

"Afraid of the Doctor addresses one of the most difficult topics any parent has to face, which is an ill child with critical health needs. Hogan and Marsac's book is a readable roadmap and instruction manual for any parent trying to get medical care for their child while also caring for their child's own emotional health," writes Emil D. Kakkis, M.D., Ph.D., CEO of Ultragenyx and a rare disease expert. "This is a must read for parents with a child suffering a significant medical disease."

More information and a media kit can be found at <u>www.afraidofthedoctor.com</u>. Please contact us for a copy of the book for review purposes or an excerpt for publication.

ABOUT MELISSA J. HOGAN

Melissa J. Hogan is the mother of three boys, the youngest of whom was diagnosed with the rare disease Hunter syndrome (MPS II) as a toddler. Soon after her son's diagnosis, she began to blog about what she was learning and her family's experience with her son's condition. The blog connected her to a community of parents around the world whose children had Hunter syndrome or other chronic conditions. In 2014, Hogan and several other parents formed the non-profit <u>Project Alive</u> and she now consults on clinical trial design and patient outcomes with <u>Doulots</u>. She earned a Juris Doctor, with a focus on health law from the University of Pittsburgh School of Law where she served as the executive editor of the *Law Review*. Prior to founding Project Alive, she worked as an attorney, a consultant on law firm strategy, and an adjunct professor of legal writing and health care regulatory law.

ABOUT MEGHAN MARSAC, Ph.D.

Dr. Meghan Marsac is a pediatric psychologist and a tenured Associate Professor at the University of Kentucky and Kentucky Children's Hospital. Dr. Marsac is a leader in the field of pediatric medical trauma, having published more than 60 academic articles and 10 chapters on this topic. Her work is represented in leading medical journals such as JAMA Pediatrics and Pediatrics and leading health psychology journals such as the Journal of Pediatric Psychology and Health Psychology. Dr. Marsac currently serves on the editorial board of the Journal of Pediatric Psychology and Journal of Traumatic Stress. She has also given hundreds of talks on understanding and promoting adjustment to injury and illness in children and their families. She is CEO of the <u>Cellie Coping</u> <u>Company</u>, which has distributed more than 2000 coping kits to families of children with medical conditions. In addition, Dr. Marsac specializes in training medical teams in the implementation of trauma-informed medical care. Clinically, Dr. Marsac implements evidence-based practices to facilitate families' management of medical treatment and emotional adjustment to challenging diagnoses and medical procedures.