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PRESS RELEASE

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TRANSLATION OF ANESTHESIA CLINICAL PRACTICE GUIDELINES FOR PATIENTS WITH SHELDON-HALL SYNDROME PUBLISHED

FAIRFAX—Recently, OrphanAnesthesia (https://www.orphananesthesia.eu/) announced the online publication of a Czech-language translation of anesthesia clinical practice guidelines for patients with Sheldon-Hall syndrome (https://www.orphananesthesia.eu/en/rare-diseases/published-guidelines/sheldon-hall-syndrome/1519-sheldon-halluv-syndrom-cz/file.html). Originally published in English, the anesthesia clinical practice guidelines

(https://www.orphananesthesia.eu/en/rare-diseases/published-guidelines/sheldon-hall-syndrome/587-sheldon-hall-syndrome/file.html) were co-authored by world-renowned DC area plastic surgeon, Dr Craig R Dufresne, MD, FACS, FICFS (https://www.duplastics.com/plastic-surgery-office/drdufresne/). OrphanAnesthesia, which publishes recommendations for anesthesia care of patients with rare disorders, is a project of the Scientific Working Group of Pediatric Anesthesia of the German Society of Anesthesiology and Intensive Care Medicine and Orphanet, a French working group of the Institute National de la Santé et de la Recherche Médicale (INSERM) devoted to rare disease information dissemination. The anesthesia clinical practice guidelines describe Sheldon-Hall syndrome (SHS), its diagnosis, typical surgeries patients undergo, special considerations before surgery, suggested anesthetic approach, potential complications, and monitoring and care after surgery.

The anesthesia clinical practice guidelines grew out of Dufresne's decade-long project on Freeman-Burian syndrome (FBS), a condition with which SHS is often confused. FBS and SHS are non-progressive muscular conditions that arise before birth and cause restricted movement in different regions of the body. Patients with SHS have a similar appearance to those with FBS, but the conditions are unique and require a different approach to treatment, with SHS being more mild and amenable to surgery. Unlike FBS, SHS is primarily a condition of the hands and feet—not the face and skull.

Dufresne has written extensively about FBS and is considered to be one of the leading experts in the world on this exceptionally rare condition, having cared for affected patients since the mid-1980s and written the only FBS clinical practice guidelines. For Dufresne writing about rare conditions is all about educating people—scientists, physicians, care teams, family members, and patients—in order to improve patients' chances for a healthy, normal, and productive life. An ever-humble gentleman, publishing medical articles is his way to help many more patients than he ever could directly.

For more information and to arrange interviews with Dufresne and a patient who has Freeman-Burian syndrome, please contact Ms Mikaela Poling, *Research Assistant*, <u>research@duplastics.com</u> or (304) 460-9038; or Mr Christopher Dufresne, *Office Manager*, <u>info@cdufresnemd.com</u> or (703) 207-3065.

Craig R Dufresne, MD, PC, with offices in Fairfax, Virginia and Chevy Chase, Maryland, is a premier private solo practice providing aesthetic and reconstructive surgery care to adults and children from across the globe. Research supports the mission to provide safe, exceptional, innovative, and compassionate care that enhances overall well-being and health.