

Principles and Framework to Guide the Development of Protocols and Standard Operating Procedures for Face and Hand Transplants

Consensus Study Lived Experience Consultants

The National Academies' Committee on Principles and Framework to Guide the Development of Protocols and Standard Operating Procedures for Face and Hand Transplants would like to acknowledge the following volunteer consultants who have been appointed to meet with the committee and provide feedback on portions of the draft consensus study report:

Sheila Advento is an amputee and a bilateral hand transplant recipient. Sheila caught Meningococemia in 2003 and went through multiple surgeries, including the amputations of all four limbs, and has used both prosthetic legs and arms. In 2010, she was the first U.S. woman to receive a bilateral hand transplant. Sheila has spoken publicly about her experiences, including through her blog, *My Life as a Quadrilateral Amputee*, and her story was published in "A Life Reclaimed: How A Quadruple Amputee Regained Control Of Her Life". She has previously helped bring together hand transplant recipients and potential recipients, and is the vice president of the Reconstructive Transplant Peer Network, a go-to resource for transplant recipients and their families.

Carmen Blandin Tarleton was brutally attacked in June of 2007, by her ex-husband. She was beaten with a baseball bat and doused with industrial strength lye. The lye burned more than 80 percent of her body, leaving her totally blind and disfigured. Now 16 years later, she has re-created herself by the power of acceptance, and forgiveness, therefore reclaiming her life. She received a second full face and neck transplant in July 2020. She continues to share her story, giving inspirational talks at several different venues.

William Lautzenheiser was a filmmaker and lecturer when, in 2011, surviving an invasive group A strep infection left him a quad amputee. Three years later, in 2014, he underwent bilateral upper extremity transplant surgery at Brigham and Women's Hospital in Boston. He has spoken publicly about his experiences as a patient and as a VCA recipient, including in an award-winning feature-length documentary, "Stumped."

Carrie (Pratt) Kinan is a caregiver of her partner who is a hand transplant recipient. Her partner was at The Station nightclub in West Warwick, Rhode Island when it caught fire during a concert in February 2003. Her partner was the most injured survivor of the fire, with third and fourth-degree burns covering nearly half of his body. He also lost his hands, ears, the sight in his left eye, and much of his nose tissue. Carrie herself was badly burned by hot coffee when she was a young child.

To learn more about the consensus study, please visit www.nationalacademies.org/face-and-hand-transplants