

<u>Principles and Framework to Guide the Development of Protocols and Standard Operating Procedures</u> <u>for Face and Hand Transplants Webinar: Panelist Biosketches</u>

March 22, 2024

Patient Panelists

Sheila Advento, is an amputee and a bilateral hand transplant recipient. Sheila caught Meningococcemia in 2003 that nearly took her life. She went through multiple surgeries, including the amputations of all four limbs (both hands and both legs below the knees). But, she eventually received her prosthetic legs in the rehabilitation center where she was transferred to. A few months after, she also received her prosthetic arms. Although Sheila struggled with the loss of independence, she soon went back to work at Quest Diagnostics, Inc., moved into her own apartment, took online college courses and pursued driving. In 2010, however, Sheila went through another major surgery. This time, she became a hand transplant recipient, making her the first woman in the USA to receive bilateral hand transplants. Sheila has accomplished many things since becoming an amputee. She, for one, had spoken to different audiences in various events - formerly NYU Amputee Support Group, a class in Kean University, Bergen Community College for the Disability Awareness Month, Hanger Educational Fair, etc. There has been some media coverage - CBS2 New York, CNN Human Factor, Discovery: Life Changing Medicine, etc. She told her story for a book called A Life Reclaimed: How A Quadruple Amputee Regained Control Of Her Life. Also, as of 2010, Sheila has shared some of her experiences through her blog called, My Life as a Quadrilateral Amputee, which also includes more talks that she had participated in. Furthermore, she created a Facebook group called Hand Transplants, as a forum to connect all of the hand transplant recipients and the potential recipients. Sheila is also an artist through drawings and through her latest challenge, painting. Now, she is also the VP of The Reconstructive Transplant Peer Network, a go-to for transplant recipients and their families.

Daniel Benner, is a hand transplant recipient. On the weekend of March 17, 2017, Benner had woken up to the feeling of having the flu. Three days later, he was in the hospital, on life support, and given the grave possibility of not surviving through this ordeal. His wife was told that he had necrotizing fasciitis with sepsis. The infection was located under his left arm and to eliminate the infection, his whole left arm, up to the clavicle, required amputation. Benner was told that he was on continuous dialysis for his failing kidneys, ventilatory support for his lungs, and numerous IV drips for the deadly infection. Unbeknownst to him, he received daily wound debridement to help deter the deadly spreading infection. The doctors informed his wife that this was a grave situation, and the probability of his survival was less than minimal at best. It was during this time that wet gangrene had set into his legs, and both required a below the knee amputation. At the same time dry gangrene had set into his only good hand that was left. A heart wrenching decision had to be made and it had to be made quickly. After months of vigorous rehab and numerous failed attempts to surgical repair what was left of his hand, he had given up hope. Benner was given a prosthetic hand to use to give him some sense of normalcy. It was very cumbersome and did not work sometimes. He was thankful for something. In 2019, Benner was made aware, that he could possibly be a candidate to receive a hand transplant from Duke University. He was contacted by Duke to come to the hospital to see if he qualifies. After going through a week of tests, he was approved, and put on the transplant list. In less than a week, he was given the extraordinary news that they had found a donor. Benner and his wife quickly made the trip from Maryland to North Carolina that afternoon to begin their new journey. On June 16, 2019, on Father's Day, after a 15-hour surgery, he had a new hand.



Robert Chelsea, became the first African American patient, and the oldest, to receive a full face transplant in a procedure at Brigham and Women's Hospital, [known today as] Mass General which is Harvard University's Medical Center, in July 2019. In August 2013, Robert Chelsea's vehicle was struck by a drunk driver. The collision and ensuing explosion left Robert severely disfigured, with third-degree burns over 60 percent of his body and face. After years of tests and physical and psychological evaluations, and a longer than usual wait for a donor, Chelsea underwent a sixteen-hour full face transplant at Brigham and Women's Hospital.

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."

Laura Nataf, lost both hands and both feet when she was 19-years-old as a result of sepsis. Laura learned to use prosthetics to perform daily tasks, but began asking her care team about hand transplantation with a goal to retrieve her independence, to get sensations back, and one day to become a mother and then hold her baby in her arms. While she was unable to receive her double hand transplant in France, she was able to turn to the hand transplant program at University of Pennsylvania. She was actively listed for transplantation May 2016 and was transplanted three months later. Laura is the first international patient to receive a double hand transplant in the United States.

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. She has appeared on many television shows and new features over the years including The Today Show, the Katie Couric show, CNN, ESPN, Aljazeer America, several episodes of The Doctor's, VPR, NPR radio, including interviews for two BBC shows. Also London's This Morning program. Her story has also been written in the New York Times, Reader's Digest, USA Today, Huffington Post and many others. Her story, featured on ESPN's E:60 news magazine was nominated for a 2015 News and Documentary Emmy. Her first book, Overcome: Burned, Blinded and Blessed, is available on Amazon.



International Panelists

Fay Bound Alberti, DPhil, FRHistS, is a Professor of Modern History at King's College London where she leads the Centre for Technology and the Body, and specialises on the history and ethics of medicine, emotion, and the body. Her books include A Biography of Loneliness: The History of an Emotion; Matters of the Heart: History, Medicine and Emotion and This Mortal Coil: The Human Body in History and Culture. Fay is frequently interviewed about her work on international news media, including ABC, CNN, BBC, and has written for publications that include TIME magazine, The Guardian and The Times. Fay's current work is a seven-year project into the history and ethics of face transplants, funded by UK Research and Innovation: Interface (previously AboutFace). This interdisciplinary and international project involves surgical teams, patients, and ethicists, alongside psychologists, philosophers and cultural theorists, to understand the social and emotional impacts of face transplants. In 2021 Fay led a Policy Lab at King's College London to establish an international consensus on best practice in the field of VCAs; that work was subsequently published in The American Journal of Transplantation.

Martin Iglesias, MD, is a Plastic and Reconstructive Microsurgeon, currently Medical Director at Orange Medical Mexico. Coordinator of the VCA program at Hospital DioMed in Mexico City. His team has performed three bilateral upper extremity transplantations, and his program is active. He was the chairman of the ISVCA Meeting 2022. He is member of the National Researcher System Level 2. Member of the National Academy of Medicine and Member of the Mexican Academy of Surgery. Member of the Mexican Association of Plastic, Aesthetic and Reconstructive Surgery; Member of the American Society of Plastic Surgeons; and Member of the International Vascularized Composite Allotransplantation Society since 2008, Member of the International Society of Plastic Regenerative Surgeon, member of the International Society of Stem Cells Research.

Simon Kay, OBE, FRCS, is a consultant plastic surgeon at Leeds Teaching Hospitals NHS Trust with a career-long record of high-quality care and innovation in children's surgery, microsurgery and nerve surgery. He now heads the UK Hand Transplant team in Leeds and led the development and implementation of that practice over the last 15 years. Kay has Chaired (President) the Boards of the two main surgical associations in his field (Hand Surgery and Plastic Surgery) and has served as Editor and Chair of a major clinical Journal (JPRAS). In these roles he has led important change of culture. Simon has edited two world leading multi-author textbooks, The growing Hand, and The Oxford Textbook of Plastic and Reconstructive Surgery. He remains the Clinical Lead in the UK Hand Transplant Unit.

Laurent Lantieri, MD, is the Professor of Plastic Surgery at Assistance Publique Hopitaux de Paris and head of department at Georges Pompidou Hospital at Paris Descartes University. Born in 1963, he went to medical school in Paris at Paris Descartes University. He became a resident in Surgery in 1986 after succeeding in the national French residency contest. In 1993 he became a research fellow at Washington University, Illinois. From 1994 to 2002 he worked at Henri Mondor Hospital and became a full Professor in 2002 and head of department in 2003. His activity is currently focused on several topics. He implanted and developed the use of the perforator microsurgical free flap in France. He took a major part in the development of the French referral center for the management of neurofibromatosis. He specialized part of his activity on the surgical management of plexiform neurofibromas and developed original techniques for facial disfigurement due to plexiform neurofibromas. He developed an original approach to face transplants in order to solve problems with previously unreconstructable faces. His team has currently performed eight of the 42 face transplants worldwide, which is the greatest number performed by a surgeon today. In 2018 Lantieri has published over 140 papers in peer reviewed journals, 9 chapters in books and one book.



Patrik Lassus, MD, is a plastic and reconstructive surgeon, head of the Department of Plastic Surgery at Helsinki University Hospital, Finland. His main clinical focus for 15 years has been in facial and head & neck reconstructive surgery and esthetic facial surgery. He is the leader of the Finnish facial allotransplant program with two face transplantations in 2016 and 2018. He became a docent in 2007 and his research focuses in reconstructive facial and head and neck surgery. The other arm in his research is focused in facial allotransplantation. He has published 75 peer reviewed articles and written chapters in 5 surgical books. He is currently the President-elect of International Society of Vascular Composite Allotransplantation

Mohit Sharma, MS, MCh, is a Plastic and Reconstructive Surgeon adept in application of microvascular techniques for solving complex reconstructive problems. After completing his specialization in Plastic and Reconstructive Surgery from Safdarjung Hospital, New Delhi in 2002, he has been serving at Amrita Hospital, Kochi since last 20 years. His team is well known for starting the first Vascularized Composite Allotransplantation (VCA) program in India in the year 2015 and has acquired one of the largest bodies of experience for any single center in the world in the field of Hand Transplantation. He has done Clinical Fellowships in Burns and Hand Surgery from St. Andrew's Centre for Plastic Surgery, which is the largest burns unit and one of the biggest reconstructive surgery units in the UK.