

Terri Coutee: ASPS Patient of Courage, 2018

Minas T. Chrysopoulou, MD, FACS



Summary: Mrs. Terri Coutee was selected as an American Society of Plastic Surgeons (ASPS) Patient of Courage in 2018. Following successful treatment of her second breast cancer, which included a double nipple-sparing mastectomy and delayed deep inferior epigastric perforator (DIEP) flap breast reconstruction, Terri changed her career path from teaching to patient advocacy. In 2016, she launched DiepCFoundation.org, a non-profit organization that provides education, support, resources, and a community for women and men seeking information about breast reconstruction after mastectomy. Today, DiepCFoundation connects patients and physicians on a global scale, fostering a shared decision-making approach to breast reconstruction. (*Plast Reconstr Surg Glob Open* 2019;7:e2451; doi: 10.1097/GOX.0000000000002451; Published online 29 October 2019.)

It is an absolute honor for me to present the background and work of Mrs Terri Coutee, a recipient of the 2018 ASPS Patient of Courage Award. Her journey navigating 2 separate breast cancer diagnoses to become a prominent patient advocate for breast reconstruction serves as an inspiration to many women and men diagnosed with, or at high risk of developing breast cancer (See [Video \[online\]](#), which presents Terri's story).

Terri chose to pursue teaching as a career and earned a degree in education. She achieved the status of Highly Qualified ESL (English as a second language) teacher and taught in 6 states across the US. (period) Countless volunteer hours included work with children ([Fig. 1](#)) and adult English language learners assisting them to integrate into the English-speaking communities in which they lived and worked.

While completing her MEd in teacher leadership, Terri received word of her second breast cancer diagnosis. The research courses in her masters' programs assisted her through her medical decision-making after her double nipple-sparing mastectomy in May of 2014. Terri decided she wanted breast reconstruction. According to 2018 procedure statistics released by the ASPS,¹ 82% of breast reconstructions performed in the United States utilize implant-based techniques. However, after researching all her options, she was most interested in DIEP flap reconstruction. The procedure uses the patient's lower abdominal skin and fat to restore a "natural," warm, soft breast after mastectomy while preserving the rectus abdominis musculature and overlying anterior abdominal wall fascia.

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By eliminating fascial and rectus muscle harvest, DIEP flaps promise improved abdominal wall stability even in patients with obesity.² Ultimately, Terri later traveled to another state for delayed bilateral DIEP flap reconstruction because the procedure was not available locally.

Terri brought many days-worth of research to her one-hour consult where she experienced a shared decision-making approach to treatment planning for the first time. Shared decision-making, as opposed to the physician making the decisions on behalf of the patient, is an approach that is gaining increasing prominence in healthcare policy globally.³⁻⁵ It occurs when the physician and patient work *together* in a collaborative way to make a healthcare decision that is best for the patient. The optimal decision takes into account evidence-based information about the available treatment options, the doctor's knowledge and experience, and the patient's individual situation, values, and personal preferences. Shared decision-making is not only a very effective approach to practicing medicine, but one that improves patient satisfaction⁶ and outcomes.⁷

Less than half of patients who undergo mastectomy feel they have made a high-quality breast reconstruction decision based on their self-reported desires.⁸ "High quality" is defined as "having knowledge of at least 50% of the important facts and undergoing treatment concordant with one's personal preferences."

Terri felt her "voice was heard" throughout her breast reconstruction journey which enabled her to make high-quality treatment decisions. Her experience in turn empowered her to do more for other women and men considering breast reconstruction. Speaking with other patients, she realized not

Disclosure: Dr Chrysopoulou is the creator of the *Breast Advocate® App*, a free shared decision-making app for breast cancer surgery and breast reconstruction treatment planning.

Related Digital Media are available in the full-text version of the article on www.PRSGlobalOpen.com.



Fig. 1. One of Terri's many classes of ESL students.

all patients shared her experience and this became the catalyst to change her career from teaching to patient advocacy.

Patient advocates help patients (and their support team) navigate their diagnosis. The National Cancer Institute partially defines a “patient advocate” as a person who “helps patients communicate with their healthcare providers so they get the information they need to make decisions about their healthcare.”⁹ Research on patient advocacy has previously focused on attempts of patient groups to mobilize resources and to positively influence research, pharmaceutical companies, and policy-makers.¹⁰ Although the primary mission may differ among advocates and advocacy groups, all advocates see education as the first step toward self-help and empowerment for those living with, or at risk of developing breast cancer.¹¹

Terri attended the Project LEAD Institute, an intensive course taught by renowned research faculty. The program provides a foundation of scientific knowledge upon which participants can first and foremost empower themselves as patient advocates. Through her training at Project LEAD, she was given a scholarship to attend the San Antonio Breast Cancer Symposium as a patient advocate to represent the breast reconstruction community (Fig. 2). Terri further advanced her advocacy skills through various training programs including the Fresh Chapter Refresh Program which teaches advocates leadership skills.

In 2016, Terri launched DiepCFoundation.org, a nonprofit organization that provides education, support, resources, and a community for women and men seeking information about breast reconstruction after mastectomy. DiepCFoundation now serves a global community of women, men, and physicians, connecting them through the Foundation's website, blog (DiepCJourney.com) and its multiple social media outlets, and via more traditional grassroots efforts (Fig. 3). The collaborative effort between the Foundation, physicians and patients continues to foster a shared decision-making approach for anyone considering breast reconstruction.

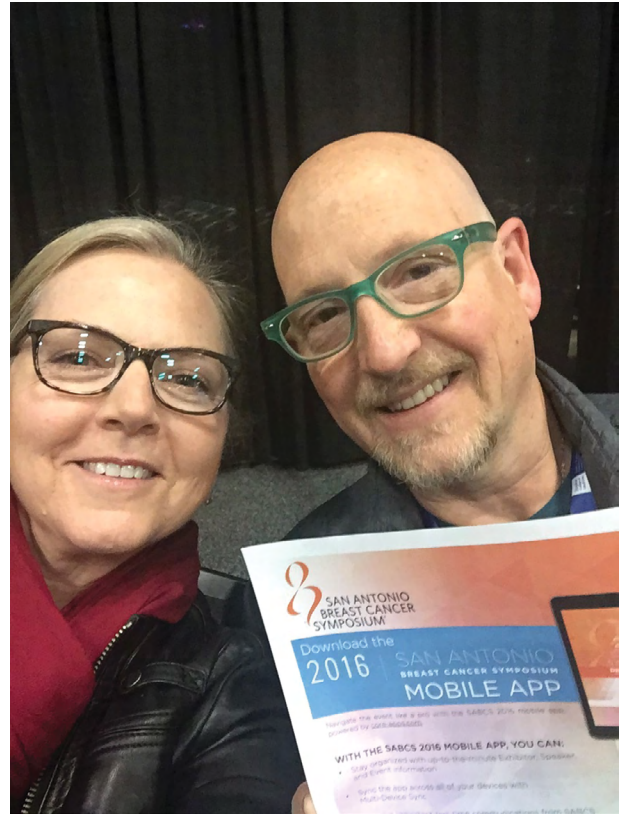


Fig. 2. Terri at the 2016 San Antonio Breast Cancer Symposium connecting with fellow Project LEAD graduate Michael Singer, a male breast cancer survivor and patient advocate from the Male Breast Cancer Coalition.

It has been incredible to witness DiepCFoundation grow and positively touch so many people. Terri strongly believes that while “not everyone chooses to have breast reconstruction, everyone deserves to be educated on *all* their options.” We could not agree more Terri. Thank you for your tireless advocacy and congratulations on your extremely well-deserved Patient of Courage Award.



Fig. 3. Terri connects with breast cancer patients seeking resources and information on breast reconstruction.

Minas T. Chrysopoulos, MD, FACS

PRMA Plastic Surgery

9635 Huebner Rd

San Antonio, TX 7824

E-mail: dr.chrysopoulos@prmaplasticsurgery.com

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