# Breast Implant Illness: Symptoms, Patient Concerns, and the Power of Social Media

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## Sir:

Despite having been temporarily removed from the U.S. market in the late 1990s, breast implants are approved for use in augmentation and reconstruction. Although it is accepted that there is an association between implants and anaplastic large cell lymphoma, breast implants have not been shown to cause autoimmune disorders or other systemic illnesses.[1](https://journals.lww.com/plasreconsurg/pages/articleviewer.aspx?year=2017&issue=11000&article=00061&type=Fulltext#R1-61),[2](https://journals.lww.com/plasreconsurg/pages/articleviewer.aspx?year=2017&issue=11000&article=00061&type=Fulltext#R2-61) However, there is a cohort of women who pursue explantation because of what is referred to as “breast implant illness,”[3](https://journals.lww.com/plasreconsurg/pages/articleviewer.aspx?year=2017&issue=11000&article=00061&type=Fulltext#R3-61) a term used to describe a constellation of symptoms and signs thought to be caused by implants.[3](https://journals.lww.com/plasreconsurg/pages/articleviewer.aspx?year=2017&issue=11000&article=00061&type=Fulltext#R3-61) There is no known pathophysiologic explanation or diagnostic testing for breast implant illness. In addition, many of these patients have very specific requests for the explantation surgery, such as performing total capsulectomy, culture of the saline inside the implants, and intraoperative photographs.

To evaluate perceptions of breast implant illness, we reviewed online activity on two breast implant illness support groups (4200 and 18,800 members, respectively) on the popular social media site Facebook. We began by focusing on content relating to breast implant illness and augmentation. Of the 345 posts and comments reviewed, 165 (48 percent) describe a symptom of breast implant illness, such as fatigue, chronic pain, rash, body odor, irregular heart rate, anxiety, neurologic abnormalities, hair loss, and endocrine dysfunction. Forty-five percent reference surgical management by asking questions, recommending surgery, or describing their experience with explantation. No post or comment expresses regret after explantation. Amidst many posts describing frustration and distrust, several members relay positive experiences and express gratitude for support from fellow “Breasties” and surgeons who listened to their concerns (Table 1).

### *Table 1*

To assess breast implant illness specifically in the setting of reconstruction, we used the search terms “mastectomy” and “reconstruction” and reviewed 73 posts. Eighty-one percent of posts mention dissatisfaction, to which there are several attributing factors: 66 percent reference unexpected illness after implant placement and 58 percent report a general feeling of unwell. Forty-four percent of posts mention pursuing implant removal, 50 percent of which describe improvement after explantation.

For both augmentation and reconstruction, Facebook group members often express frustration with plastic surgeons when there is a perceived dismissal of symptoms (Table 2). Some symptoms may be attributable to indolent infection after implant placement, and surgeons should maintain a high index of suspicion for infections caused by atypical organisms.[4](https://journals.lww.com/plasreconsurg/pages/articleviewer.aspx?year=2017&issue=11000&article=00061&type=Fulltext#R4-61) Individuals’ comorbidities should be evaluated to rule out unrelated causes. The thousands of individuals who share experience, seek support, and express frustration on social media, and the contrast in attitudes toward plastic surgeons expressed in posts found in Tables 1 and 2, suggest a gap in communication between many patients and their surgeons. We recommend validation of individual concerns and educating patients that we currently do not know of a mechanism by which implants can cause any of these systemic symptoms.[2–5](https://journals.lww.com/plasreconsurg/pages/articleviewer.aspx?year=2017&issue=11000&article=00061&type=Fulltext#R2-61) However, surgeons should consider respecting the patient’s wishes, removing the implants, and informing the patient that roughly half of women with symptoms of breast implant illness may improve after explantation.

[Ann Rheum Dis](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1754147/). 2002 Jul; 61(7): 659.

doi:  [[10.1136/ard.61.7.659](https://dx.doi.org/10.1136/ard.61.7.659)]

[Plast Reconstr Surg.](https://www.ncbi.nlm.nih.gov/pubmed/11176625) 2001 Jan;107(1):206-13.

**Self-reported symptoms among women after cosmetic breast implant and breast reduction surgery.**

[Fryzek JP](https://www.ncbi.nlm.nih.gov/pubmed/?term=Fryzek%20JP%5BAuthor%5D&cauthor=true&cauthor_uid=11176625)1, [Signorello LB](https://www.ncbi.nlm.nih.gov/pubmed/?term=Signorello%20LB%5BAuthor%5D&cauthor=true&cauthor_uid=11176625), [Hakelius L](https://www.ncbi.nlm.nih.gov/pubmed/?term=Hakelius%20L%5BAuthor%5D&cauthor=true&cauthor_uid=11176625), [Feltelius N](https://www.ncbi.nlm.nih.gov/pubmed/?term=Feltelius%20N%5BAuthor%5D&cauthor=true&cauthor_uid=11176625), [Ringberg A](https://www.ncbi.nlm.nih.gov/pubmed/?term=Ringberg%20A%5BAuthor%5D&cauthor=true&cauthor_uid=11176625), [Blot WJ](https://www.ncbi.nlm.nih.gov/pubmed/?term=Blot%20WJ%5BAuthor%5D&cauthor=true&cauthor_uid=11176625), [McLaughlin JK](https://www.ncbi.nlm.nih.gov/pubmed/?term=McLaughlin%20JK%5BAuthor%5D&cauthor=true&cauthor_uid=11176625), [Nyren O](https://www.ncbi.nlm.nih.gov/pubmed/?term=Nyren%20O%5BAuthor%5D&cauthor=true&cauthor_uid=11176625).

[**Author information**](https://www.ncbi.nlm.nih.gov/pubmed/11176625)

**Abstract**

A retrospective cohort study was performed in Sweden to evaluate the possibility that an individual symptom or constellation of illness symptoms related to silicone occurs in women after breast implant surgery. A random sample (n = 2500) of all women in the Swedish national implant registry who underwent breast augmentation surgery with alloplastic breast implants during the years 1965 through 1993 was compared with a sample (n = 3500) of women who underwent breast reduction surgery during the same period, frequency matched to the implant patients for age and calendar year at the time of surgery. In total, 65 percent of the breast implant patients (n = 1546) and 72 percent of the breast reduction patients (n = 2496) completed a self-administered questionnaire covering 28 rheumatologic and other symptoms and lifestyle and demographic factors. Practically all of the 28 symptoms inquired about were reported more often by women in the breast implant cohort, with 16 (57 percent) significantly more common in breast implant recipients. In contrast, few significant differences or consistent patterns were observed in the length of time since the implant and in the type (silicone or saline) or volume of the implant. Although women with breast implants report a multitude of symptoms more often than women who have breast reduction surgery, the lack of specificity and absence of dose-response relationships suggest that the excess of reported symptoms is not causally related to cosmetic implants.

[Plast Reconstr Surg.](https://www.ncbi.nlm.nih.gov/pubmed/10845310) 2000 Jun;105(7):2529-37; discussion 2538-43.

**A prospective analysis of patients undergoing silicone breast implant explantation.**

[Rohrich RJ](https://www.ncbi.nlm.nih.gov/pubmed/?term=Rohrich%20RJ%5BAuthor%5D&cauthor=true&cauthor_uid=10845310)1, [Kenkel JM](https://www.ncbi.nlm.nih.gov/pubmed/?term=Kenkel%20JM%5BAuthor%5D&cauthor=true&cauthor_uid=10845310), [Adams WP](https://www.ncbi.nlm.nih.gov/pubmed/?term=Adams%20WP%5BAuthor%5D&cauthor=true&cauthor_uid=10845310), [Beran S](https://www.ncbi.nlm.nih.gov/pubmed/?term=Beran%20S%5BAuthor%5D&cauthor=true&cauthor_uid=10845310), [Conner WC](https://www.ncbi.nlm.nih.gov/pubmed/?term=Conner%20WC%5BAuthor%5D&cauthor=true&cauthor_uid=10845310).

[**Author information**](https://www.ncbi.nlm.nih.gov/pubmed/10845310)

**Abstract**

Despite the lack of a scientifically proven link between silicone implants and disease, many women have chosen to have their implants removed out of concern for their health. Unfortunately, there are few studies in the literature that have investigated the outcome of explanations, and there are no prospective analyses of the effect explantation has on a patient's general health. The goal of this study was to use a prospective database to determine whether there were any preoperative parameters that could be used to predict which patients would be improved following removal of silicone breast implants and to provide a quantifiable measure of that improvement. A total of 38 patients with silicone breast implants underwent operative removal of their breast implants by faculty at the University of Texas Southwestern Medical Center. They were given questionnaires regarding several personal and medical parameters to be completed preoperatively, at 6 weeks postoperatively, and at 6 months postoperatively. In addition, their physicians completed preoperative and postoperative evaluations of the patient's general health status. A control group of 38 patients was established; they were matched with the experimental group with regard to age and other initial parameters. Their responses to questionnaires were then grouped according to standard subscales to evaluate physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role, mental health, appearance evaluation, appearance orientation, illness orientation, and body area satisfaction. When compared with the control group, we found that patients who had undergone explantation showed a temporary decrease in musculoskeletal symptoms and bodily pain, as well as an increase in vitality, mental health, and body area satisfaction. Of the experimental group, those who initially indicated a higher number of musculoskeletal symptoms and a higher appearance evaluation were more likely to indicate a significant improvement in general health since explantation.

[Ann Plast Surg.](https://www.ncbi.nlm.nih.gov/pubmed/1622027) 1992 May;28(5):491-9; discussion 499-501.

**Silicone breast implants and immune disease.**

[Shons AR](https://www.ncbi.nlm.nih.gov/pubmed/?term=Shons%20AR%5BAuthor%5D&cauthor=true&cauthor_uid=1622027)1, [Schubert W](https://www.ncbi.nlm.nih.gov/pubmed/?term=Schubert%20W%5BAuthor%5D&cauthor=true&cauthor_uid=1622027).

[**Author information**](https://www.ncbi.nlm.nih.gov/pubmed/1622027)

**Abstract**

Silicone was originally regarded as inert in the human body. Silicone medical devices have been associated with various complications that may involve an immune reaction to silicone or a silicone organic complex. There have been more than 80 cases reported in the medical literature of a varied systemic autoimmune illness in patients who have had various foreign materials placed in the breast. Controversy exists as to which complications have a cause and effect relationship, and which represent coincidental findings. It is difficult to distinguish between nonspecific local reactions and reactions that have an immunological basis. Approximately 1,000,000 to 2,000,000 women in the United States have had silicone breast implants inserted for reconstruction or augmentation mammaplasty; 28 of those patients have been reported to have developed a systemic autoimmune disease. Data on the 28 reported cases do not in any way prove a causal relationship between breast implants and immune disease. Given the natural incidence of autoimmune diseases, we would expect a coincidental occurrence in the United States of more than 1,000 cases of autoimmune disease in women who had undergone breast implant surgery. Additional information must be obtained to resolve the question. The true incidence of autoimmune disease in patients with implants needs to be determined. A prospective registry of implant patients should be established and comprehensive retrospective information obtained on the implant patient population. Further experimental work is necessary on the bioreactivity of silicone. Patients with implants and autoimmune disease, once identified, must be carefully evaluated by physicians who are experienced in the treatment of autoimmune disease.

[Ann Intern Med.](https://www.ncbi.nlm.nih.gov/pubmed/?term=Long-term+health+outcomes+in+women+with+silicone+gel+breast+implants%3A+a+systematic+review.+Ann+Intern+Med.+2016%3B164%3A164%E2%80%93175.+13.+Eaves+FF%2C+Rohrich+RJ%2C) 2016 Feb 2;164(3):164-75. doi: 10.7326/M15-1169. Epub 2015 Nov 10.

# Long-Term Health Outcomes in Women With Silicone Gel Breast Implants: A Systematic Review.

[Balk EM](https://www.ncbi.nlm.nih.gov/pubmed/?term=Balk%20EM%5BAuthor%5D&cauthor=true&cauthor_uid=26550776), [Earley A](https://www.ncbi.nlm.nih.gov/pubmed/?term=Earley%20A%5BAuthor%5D&cauthor=true&cauthor_uid=26550776), [Avendano EA](https://www.ncbi.nlm.nih.gov/pubmed/?term=Avendano%20EA%5BAuthor%5D&cauthor=true&cauthor_uid=26550776), [Raman G](https://www.ncbi.nlm.nih.gov/pubmed/?term=Raman%20G%5BAuthor%5D&cauthor=true&cauthor_uid=26550776).

### Abstract

#### BACKGROUND:

Silicone gel breast implants were removed from the U.S. market for cosmetic use in 1992 owing to safety concerns. They were reintroduced in 2006, with a call for improved surveillance of clinical outcomes.

#### PURPOSE:

To systematically review the literature regarding specific long-term health outcomes in women with silicone gel breast implants, including cancer; connective tissue, rheumatologic, and autoimmune diseases; neurologic diseases; reproductive issues, including lactation; offspring issues; and mental health issues (depression and suicide).

#### DATA SOURCES:

MEDLINE, EMBASE, and Ovid Healthstar (inception through 30 June 2015), and the Cochrane Central Register of Controlled Trials and Cochrane Database of Systematic Reviews (through the first quarter of 2015).

#### STUDY SELECTION:

4 researchers double-screened articles for longitudinal studies that compared women with and without breast implants and reported long-term health outcomes of interest.

#### DATA EXTRACTION:

4 researchers extracted data on participant and implant characteristics, analytic methods, and results.

#### DATA SYNTHESIS:

32 studies (in 58 publications) met eligibility criteria. Random-effects model meta-analyses of effect sizes were conducted when feasible. For most outcomes, there was at most only a single adequately adjusted study, which usually found no significant associations. There were possible associations with decreased risk for primary breast and endometrial cancers and increased risks for lung cancer, rheumatoid arthritis, Sjögren syndrome, and Raynaud syndrome. Evidence on breast implants and other outcomes either was limited or did not exist.

#### LIMITATION:

The evidence was most frequently not specific to silicone gel implants, and studies were rarely adequately adjusted for potential confounders.

#### CONCLUSION:

The evidence remains inconclusive about any association between silicone gel implants and long-term health outcomes. Better evidence is needed from existing large studies, which can be reanalyzed to clarify the strength of associations between silicone gel implants and health outcomes.

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**US FDA Breast Implant Postapproval Studies**

Long-term Outcomes in 99,993 Patients

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Objective: To analyze the long-term safety and efficacy outcomes of patients with breast implants.
Summary Background Data: Research is ongoing regarding the safety of silicone breast implants. Despite the number of patients with breast implants followed by United States Food and Drug Administration large postapproval studies (LPAS), this database has not been thoroughly analyzed or reported. Methods: This is a multicentered, cohort study. LPAS prospectively monitor long-term implant-related outcomes and systemic harms for silicone/saline implants from 2 manufacturers (Allergan and Mentor) placed for primary/ revision augmentation/reconstruction. Systemic harms, self-harm, and reproductive outcomes are compared with normative data. Implant-related com- plications are analyzed by implant composition and operative indication in the short and long terms.

Results: LPAS data includes 99,993 patients, 56% of implants were silicone for primary augmentation. Long-term magnetic resonance imaging surveillance is under 5%. Compared with normative data, silicone implants are associated with higher rates of Sjogren syndrome (Standardized incidence ratio [SIR]8.14), scleroderma (SIR 7.00), rheumatoid arthritis (SIR5.96), stillbirth (SIR4.50), and melanoma (SIR3.71). One case of BI-ALCL is reported. There is no association with suicide. In the short term, rupture is higher for saline (2.5% vs. 0.5%, P < 0.001), and capsular contracture higher for silicone (5.0% vs. 2.8%, P < 0.001). At 7 years, reoperation rate is 11.7% for primary augmentation, and 25% for primary/revision reconstruction. Capsular contracture (III/IV) occurs in 7.2% of primary augmentations, 12.7% primary reconstructions, and is the most common reason for reoperation among augmentations.

Conclusions: This is the largest study of breast implant outcomes. Silicone implants are associated with an increased risk of certain rare harms; associations need to be further analyzed with patient-level data to provide conclusive evidence. Long-term safety and implant-related outcomes should inform patient and surgeon decision-making when selecting implants