This fact sheet explains what the SUI Surgery Module is, how your surgeon is improving care for women with urinary incontinence by participating in the Module, and how you can make your voice heard as part of this initiative. Better care matters to everyone, and we want you to join the effort!

THE SUI SURGERY MODULE

The American Urogynecologic Society in collaboration with the Medical Device Epidemiology Network, a global public-private partnership, has developed the SUI Surgery Module. This registry module collects real-world data, including patient-reported data, to strengthen surveillance and improve outcomes of stress urinary incontinence surgery. Collecting this information will help identify trends in surgery and suggest areas of improvement for surgeons.

This registry module will help surgeons across the country track how they are doing and how the medical devices they implant behave. Your participation will improve care for thousands of women just like you by identifying surgical practices that give the best outcomes for patients and gathering information about the devices used in SUI surgeries. This information will directly benefit you in the event that new information is available about your medical device, and we hope it will help you start important conversations with your provider.

Frequently Asked Questions

- **What do I have to do to participate?**
  All you have to do is complete the brief questionnaire when it is emailed to you. Five weeks after your surgery, you’ll get a survey from suicommunity@augs.org. Click on the link in the email and create a password for your secure Patient Portal then answer 6 questions about your health. That’s it!

- **How will the SUI Surgery Module help me?**
  You’ll be part of an effort to improve care for all women undergoing SUI surgery. The information collected in the registry can identify potential areas of improvement for surgeons, as well as potential complications. The SUI Surgery Module questionnaires you complete can be an important tool to start conversations with your surgeon if you’re concerned about your health after surgery and will inform your surgeon about how best to provide follow-up care to you. The registry will also provide new information about your surgical procedure or medical device implant to improve your follow-up care.

  You’ll also be enrolled in a community of women who are also having SUI surgery and you’ll have access to a wealth of resources about your condition. You can communicate with other women who have had the same surgery and ask questions. Some sites even offer an incentive for patients to participate.

- **What kind of information will be collected in the SUI Surgery Module?**
  Your surgeon will put in basic data about you and your procedure, including your email address for follow-up, your medical history and some information about your surgery including whether or not you had a device implanted. If you did have a device implanted, the registry collects information about the device such as manufacturer and date of
production. You will have the chance to tell us about any complications you’ve experienced, how satisfied you were with your surgery and whether you would do anything differently.

• **Is my personal information safe in the registry module? Who can see it?**

Your data, including your name or email address as well as your health information, is completely secure and is never shared with anyone. Once your data is in the registry, your personal identifiable information is hidden and your data is de-identified. That means if the SUI Surgery Module dataset is used to measure rates of complication or to do research about best surgical practices, no one would be able to tell what data was yours.

You will be invited to participate in a community of women having SUI surgery. If you participate in the patient community, you may receive emails when new discussions are posted, or if there are any changes to the registry itself. Otherwise, the only contact you’ll receive is the follow-up questionnaire about your health post-surgery.

No one can see your data except your surgeon or his or her designated representative (such as nurse or physician assistant). Your physician will not disclose your information except as required by law.

• **Will the information in the SUI Surgery Module be used for anything else?**

The information in the SUI Surgery Module could be used at a later date for research such as assessing whether complications occur more frequently in women who smoke, or what the best way to treat recurring pain after surgery is. Surgeons who participate in the SUI Surgery Module will receive reports about their performance compared to their peers. Surgeons can also use the information in the registry to learn more about their patients and common complications their patients are experiencing in real time.

• **What if I change my mind about participating?**

If at any time you decide you don’t want to receive the survey, you can unsubscribe by clicking the link in the email you receive, or emailing suicommunity@augs.org. Or simply inform your provider the next time you see him or her. Information you provided prior to withdrawing will remain in the registry.

• **Where can I find more information about SUI? About the module?**

Visit Voices for PFD at www.voicesforpfd.org and click on the Resources link. You’ll also receive an invitation to be part of a closed SUI surgery-specific community that will have additional information about the module and about SUI surgery. You can ask questions of other women who have had the same surgery as you.

• **What if there’s a problem after my surgery? Can the module help?**

If you have any concerns about your health after your surgery, contact your provider immediately. We hope the questionnaires you complete will help start important conversations with your surgeon if you have questions or issues post-surgery. Your participation will improve care for thousands of women just like you by identifying surgical practices that give the best outcomes for patients and gathering information about the devices used in SUI surgeries.

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**For More Information**

Additional questions? Visit Voices for PFD at voicesforpfd.org, the SUI Surgery Patient Community or email suicommunity@augs.org