

## GETTING TO THE SCN8A REGISTRY QUESTIONNAIRE

The following steps guide you on how to Join the SCN8A Community, Access the Registry, and Save the information you input.

- Step 1: Joining the SCN8A Community Website
- Step 2: Accessing the SCN8A Registry Questionnaire
- Step 3: Saving your information

For any troubleshooting issues, please contact Dr. Hammer or the Clinical Coordinator at [scn8a.info@gmail.com](mailto:scn8a.info@gmail.com) with subject line "REGISTRY HELP"

### STEP 1: JOINING THE SCN8A COMMUNITY WEBSITE

1. Go to [scn8a.net](http://scn8a.net)
2. On the top bar menu, select Registry



3. At the bottom of the page, select Create an account
  - a. Enter all the required information to verify your account, then select Create an account

**Create an account**

4. Choose a username and password. Note: the username is case sensitive:

Username\*: \_\_\_\_\_  
Password\*: \_\_\_\_\_

5. Genetic Variant information. To confirm that you or your child has a variant in SCN8A, you must provide two pieces of information that can be found on your genetic report.

cDNA\* (number only): \_\_\_ example: c.4360A>G, enter 4360 \_\_\_  
Variant\* (number only): \_\_\_ example: p.N1877S or Asn1877Ser, enter 1877 \_\_\_

If you don't have this information, please contact us at [scn8a.info@gmail.com](mailto:scn8a.info@gmail.com)

6. After your account has been created, you will receive an email confirmation. This is a good opportunity to make sure to save your username and password.

### STEP 2: ACCESSING THE SCN8A REGISTRY QUESTIONNAIRE

1. Log into the [scn8a.net](http://scn8a.net) website using your username and password
2. On the top bar menu, select Registry

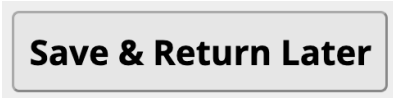


3. On the bottom of the page, select Go to the Registry Questionnaire

**Go to Registry Questionnaire**

### **STEP 3: SAVING YOUR INFORMATION**

1. The questionnaire is using a log-in system to save and return later to a questionnaire. Prior to leaving the Registry Questionnaire, you must select Save & Return Later



2. You will get a notification stating that your results have been saved. Please input your email address to receive a unique link to your information

**Your survey responses were saved!**

You have chosen to stop the survey for now and return at a later time to complete it. To return to this survey, you will need the survey link to this survey.


**Survey link for returning**  
You may bookmark this page to return to the survey, OR you can have the survey link emailed to you by providing your email address below. If you do not receive the email soon afterward, please check your Junk Email folder.

\* Your email address will not be stored

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Or if you wish, you may continue with this survey again now.

3. You will get a confirmation statement when the email is sent. We suggest that you bookmark the link in your browser to return to the Registry Questionnaire
4. To return back to the Registry Questionnaire, you must type your Full Name and Email Address

 **Survey Login** ✕

Survey title: "SCN8A Registry Questionnaire"

Before beginning or continuing this survey, you must first log in by successfully entering the correct values below. **You must successfully enter a value for ALL the fields below.** Please note that the login is \*not\* case sensitive.

**Full Name:**   
 Show value

**E-mail:**   
 Show value

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If you forget your log in information, please contact [scn8a.info@gmail.com](mailto:scn8a.info@gmail.com)

