

- What is a PIN?
- Registration process
 - Privacy/Security
 - Opt in/or out of sharing in part or a whole
 - Adding family members easily
- Profile page view
 - Modules: Add healthcare provider / medical records / send us an email
 - ClinGen Data Sharing – why consent?
- Why Join?
 - For your family
 - View Data / Survey exports / Records gathered
 - Hear about research relevant to the Hist1H1E community
 - For the Hist1H1E community
 - Infographic for Hist1H1E
 - Sharing data with researchers to speed diagnosis, treatments and cures
 - Create a valued community of families that are research ready

Welcome to the Hist1H1E Syndrome Patient Insights Network

LOGIN

REGISTER



<https://connect.invitae.com/en/?org=hist1h1E>

Account registration page

- Click JOIN on the homepage to register
- Complete initial information, which you can edit at any time
- Return to your email for verification
- Follow the email link to log in!



Select Language | ▼

HOME LEARN MORE ▼ SIGN IN SIGN UP

Message

Your account is created but requires activation. Please follow the instructions sent to you by email.

Login

Account Registration

Invitae PIN collects health information in a way that protects your privacy and allows you to control access to your information. To register, you must meet one of the following:

- Have or be at risk to develop a health condition, be age 18 or older and be able to make your own medical decisions
- Represent a child or dependent who has or is at risk to develop a health condition and for whom you can legally make medical decisions.

[Questions about privacy?](#)

* The fields with the asterisk are required.

Your First Name	<input type="text"/>	*
Your Last Name	<input type="text"/>	*
Preferred Language	<input type="text"/>	* i
Your Relationship to Participant	<input type="text"/>	i
Email	<input type="text"/>	* i
Confirm Email	<input type="text"/>	* i
Username	<input type="text"/>	* i
Password	<input type="text"/>	Show * i

Please enter a valid password. No spaces, at least 8 characters and contain at least 1 lower-case letter, 1 upper-case letter, 1 number, and 1 symbol character



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Invitae Connect PIN Sign Up

To: You

Dear a,

Thank you for creating an Invitae CONNECT account. Please complete the set-up process by clicking on this link:

<https://na01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fconnect.invitae.com%2Fen%2Fcb-profile%2Fconfirm.html%3Fconfirmcode%3Drege1678e17a2c574018de5d57e7771d7e4078ca02e&data=05%7C01%7C%7C20283dd0e6044e7d66ef08db4cac4355%7C84df9e7fe9f640afb435aaaaaaaaaaaa%7C1%7C0%7C638188074962135335%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6IjEhaWwiLCJXVCi6Mn0%3D%7C3000%7C%7C%7C&sdata=uY3n8qhbbyqhgFABWjPTG1bA1X4ONIhgQWD5qdxGHf0%3D&reserved=0>

After clicking on the link above you will be redirected to the Connect activation process is complete.

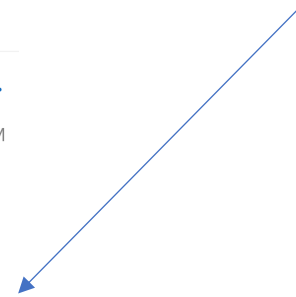
Please contact us if you have questions or believe you have received an error.

The Invitae Phenomics Team

<https://na01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fconnect.invitae.com%2Fen%2Fcb-profile%2Fconfirm.html%3Fconfirmcode%3Drege1678e17a2c574018de5d57e7771d7e4078ca02e&data=05%7C01%7C%7C20283dd0e6044e7d66ef08db4cac4355%7C84df9e7fe9f640afb435aaaaaaaaaaaa%7C1%7C0%7C638188074962135335%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6IjEhaWwiLCJXVCi6Mn0%3D%7C3000%7C%7C%7C&sdata=uY3n8qhbbyqhgFABWjPTG1bA1X4ONIhgQWD5qdxGHf0%3D&reserved=0>



Thu 5/4/2023 7:31 AM



- Email verification link leads back to the log in screen, where your username and password are ready to use



PATIENT INSIGHTS NETWORK™

Select Language

HOME

LEARN MORE

SIGN IN

SIGN UP

Message

Your account is activated and you may now log in.

Login

Participant details page

- Complete the registration process
- Safely and securely enter information about the person with Hist1H1E
- Click submit to see your profile page!

Message

Missing required fields. Please complete your profile.

Have questions about your participation or want to withdraw your participation? [Click here](#)

The link leads to a webform that will allow you to notify us of your intention to withdraw.

Participant

The person with or at risk for the health condition

Health Reason for Registration	HIST1H1E Syndrome	*
Other Reason for Registration	HIST1H1E Syndrome	
Participant's First Name		* i
Participant's Middle Name		i
Participant's Last Name		* i
Sex assigned at birth		* i
Gender		i
Birthdate		i * i
Race (Select all that apply)	<input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Black or African American	

Privacy and Security (see the FAQ page)

<https://connect.invitae.com/en/learn-more/frequently-asked-questions.html>

Who will have access to my PIN information?

Your privacy is our priority. Only trained PIN managers will have access to your identifying information. You can set your sharing preferences for each survey that you complete. You can also change your sharing preferences at any time. All personal identifiers, such as your name or email address, are removed before your answers are shared. We built our systems to make sure your data is safeguarded.

In accordance with your contact preferences, your email address will only be used by Invitae for direct messages.

How will my identity be protected?

All personal identifiers, such as your name or email address, are removed before your information is shared unless you ask us to disclose your contact information.

Who owns the data?

You own your data. Patients opt in and choose to share their information, and they can just as easily opt out. We are grateful that so many PIN participants are willing to share their information to support research.

Who, besides me, can access the data?

With your permission, de-identified information is made available to the greater medical community, including non-profit organizations, advocacy groups, doctors, research scientists, medical investigators, regulatory agencies, pharmaceutical, biotech, and biomedical companies.

Can I withdraw if I change my mind?

Yes. You can change your sharing preferences or ask to withdraw your information from the PIN in full at any time. De-identified information shared before you leave the PIN cannot be recalled.

Who should I contact if I have any questions?

Please contact us at connect@invitae.com if you have any questions.

Your PROFILE page

See your PROFILE page to:

Take surveys about your family's experience

Easily add additional affected family members without re-registering

Search for or add your healthcare provider information

Access your account information

Send the PIN Coordinator a message

HOME LEARN MORE ▾ VIEW DATA PROFILE LOGOUT

Welcome back, Jo Anne!




You do not have to complete the survey at one time. You may log out at any time and your answers will be saved. For more detailed instruction, [click here](#).

Health Surveys

TO DO


[General Health](#) START SURVEY >

COMPLETED

Family History Survey completed 05-04-2023 Download results Update survey	 VIEW DATA History
Medical Care Survey Survey completed 05-04-2023 Download results Update survey	 VIEW DATA History
ClinGen Data Sharing Informed Consent Survey completed 05-04-2023 Download results Update survey	 VIEW DATA History

Family Members

Easily add minor-aged children or dependents. Manage these accounts with one username and password.


[ADD FAMILY](#)

Healthcare Providers

Add your healthcare providers to help other participants learn which medical professionals see people with the same condition.

VIEW DATA tab in the main menu bar

- Offers an opportunity to see a generalized map of participants in the PIN (no locations are shared)
- Opportunity to see charts and graphs of where your survey answers sit among all the Hist1H1E families that answered the same question
- Filter your charts by diagnosis, by age, by gender etc. to dive deeper into the data

PIN PARTICIPANTS

Participant Map

SAVED FILTERS

No filter published

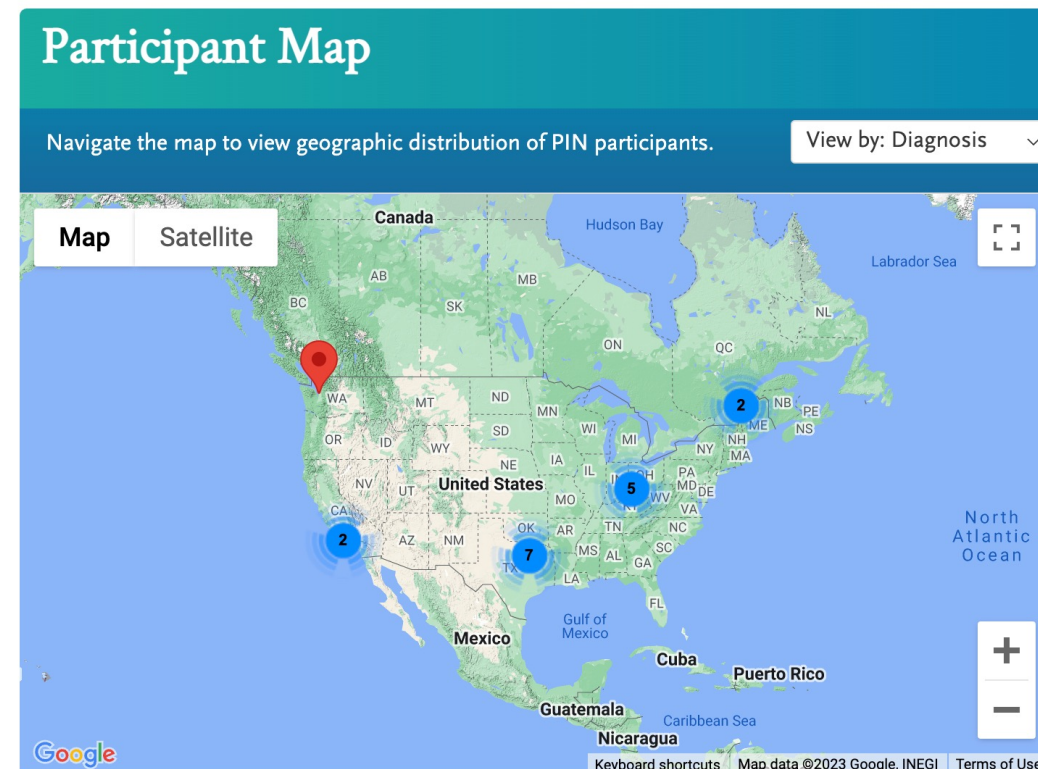
COMPLETED SURVEYS

- + Family History
- + Medical Care Survey
- + ClinGen Data Sharing Informed Consent

INCOMPLETE SURVEYS

Complete these surveys to view and compare data.

[General Health](#)



About Survey Data

Explore the data from surveys offered through this PIN. Simply click on the name of the survey and select the page of questions that you wish to view. If you haven't completed your survey, unlock the data by completing your survey today. Consider these helpful hints as you browse:

- Topic pages
Seeing a page that was not in your version of the survey? To keep the survey as personalized as possible, our surveys branch to skip pages that are not relevant based on the answers that you provide. This survey data section shows the answers from participants for all pages.


Share your Genetic Test Results



Help clinicians and researchers better understand genomics by giving patients a way to share their genetic test results safely and securely with ClinGen, an NIH-funded resource.


Why share genetic test results

When a laboratory finds a genetic change (variant) for the first time, they often know little about it. Even if a genetic variant is well understood, data sharing helps increase understanding of a condition's features, which may help identify possible interventions and treatments.




HELP CLINICIANS, RESEARCHERS, & PATIENTS

Increase understanding of your condition and what to expect in the future



STAY UPDATED

Receive updates about your genetic test results when there is new information



MAKE A DIFFERENCE

Help others with the same condition get more definitive results from genetic testing

The more information we collect, the better we will understand how genes affect health and, ultimately, how best to care for patients.

WHO IS CLINGEN?

ClinGen is a National Institutes of Health (NIH)-funded resource dedicated to building an authoritative central resource that defines the clinical relevance of genes and variants for use in precision medicine and research. This resource relies on data sharing. Patient health information that ClinGen helps to share is de-identified and securely stored.

- Take the consent survey on your profile:

ClinGen Data Sharing Informed Consent

Survey completed 05-04-2023 [Download results](#) | [Update survey](#)

- Upload a pdf of genetic testing results:

Testing Results

Upload relevant medical records to share more detailed data while protecting your privacy.



[ADD MEDICAL RECORDS](#)

- Your test results will be curated and contributed to ClinGen
- YOU choose to be updated if any new information is discovered about your specific results

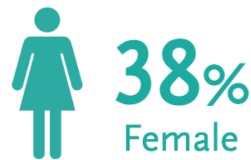
Patients living with: HIST1H1E Syndrome

Data highlights from the Invitae Patient Insights Network

Who are we?



Patients: **42** Ages: **<1 to 22**



Impact on our lives



Getting diagnosed



Initial symptoms



- ✓ Developmental delays
- ✓ Other
- ✓ Gastrointestinal problems

Average age at diagnosis

Patients living with: HIST1H1E Syndrome

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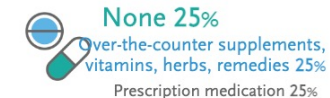
Frequent doctor visits



Major episodes of care



A combination of treatments



Getting diagnosed



Initial symptoms



- ✓ Developmental delays
- ✓ Other
- ✓ Gastrointestinal problems

Average age at diagnosis



7 Year(s) old



Extensive testing

- Genetic Testing
- MRI
- Blood tests
- Physical examination
- CT scan



Different types of tests



Diagnosing specialty

- Genetics
- Neurology

Patients everywhere are eager to help find better treatments



83% want to be contacted about trials

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