



PIN DATA PORTAL

[HTTPS://PINDATA.INVITAE.COM/](https://pindata.invitae.com/)
SEPTEMBER 2017



PIN Data Portal

PUT PATIENT REPORTED DATA TO WORK FOR YOU

As an interested stakeholder you have access to charts, graphs and see aggregate data on the medical conditions of interest to you.

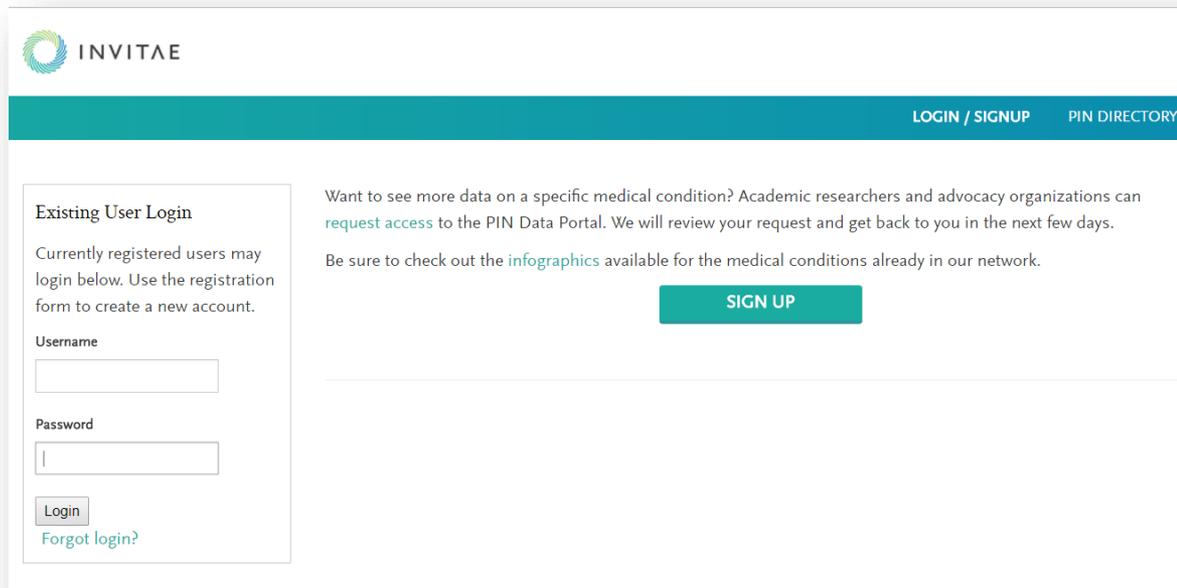
Create an account here: <https://pindata.invitae.com/>

Click “SIGN UP” to create your account.

Select the medical conditions of interest on your account set-up screens.

You will be notified by email of account approval within 2 business days.

Then, return as an “Existing User”



The screenshot shows the Invitae PIN Data Portal interface. At the top left is the Invitae logo. A teal navigation bar contains the links "LOGIN / SIGNUP" and "PIN DIRECTORY". On the left, there is a "Existing User Login" section with a text box explaining that currently registered users can login and new users can create an account. It includes input fields for "Username" and "Password", a "Login" button, and a "Forgot login?" link. In the center, there is a teal "SIGN UP" button. To the right of the button, there is text explaining that academic researchers and advocacy organizations can request access to the portal, and that infographics are available for existing medical conditions.

PIN Data Portal

SURVEY GRAPHS AND CHARTS

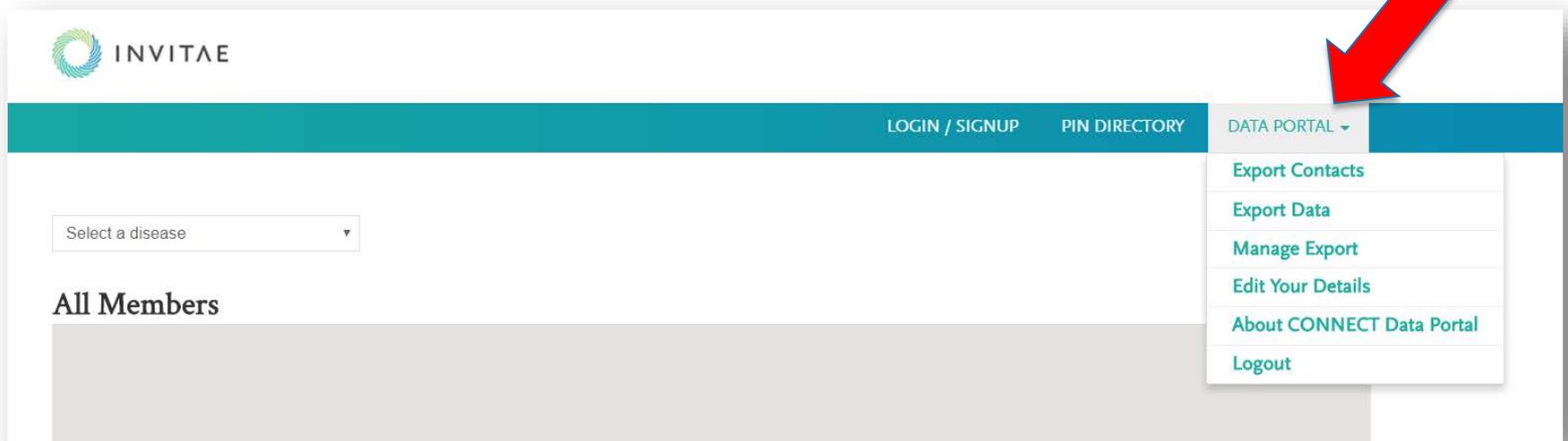
The screenshot displays the PIN Data Portal interface. At the top, three grey boxes labeled "Choose Medical Condition", "Choose Survey", and "Choose Topic" have arrows pointing to the filter dropdowns. The navigation bar includes "LOGIN / SIGNUP", "PIN DIRECTORY", and "DATA PORTAL". The filter dropdowns are set to "MPS I Hurler Syndrome", "Diagnosis", and "Diagnosis - Page 1". Below the filters, there are links for "Map - Export". The main content area features a horizontal bar chart titled "At what age was the diagnosis made?". The chart shows the number of responses for different age groups: 0-3 months old (1), 4-7 months old (9), 8-11 months old (17), 1 year old (18), 2 years old (4), and 3 years old (2). The x-axis represents the number of responses, ranging from 0 to 15. A note below the chart states "52 people provided 52 responses".

Age Group	Number of Responses
0 - 3 months old	1
4 - 7 months old	9
8 - 11 months old	17
1 year old	18
2 years old	4
3 years old	2

See
Charts
and
Graphs

PIN Data Portal

DATA AND CONTACT EXPORT



The screenshot displays the INVITAE PIN Data Portal interface. At the top left is the INVITAE logo. The navigation bar includes links for 'LOGIN / SIGNUP', 'PIN DIRECTORY', and 'DATA PORTAL'. A red arrow points to the 'DATA PORTAL' dropdown menu, which is open and shows the following options: 'Export Contacts', 'Export Data', 'Manage Export', 'Edit Your Details', 'About CONNECT Data Portal', and 'Logout'. Below the navigation bar, there is a dropdown menu labeled 'Select a disease' and a section titled 'All Members'.

- Click on [DATA PORTAL](#) to see the menu displayed above.
- Choose [Export Contacts](#) to export email address of participants that wish to share.
- Choose [Export Data](#) to download row level de-identified survey data.

PIN Data Portal – data export screens

INVITAE

LOGIN / SIGNUP PIN DIRECTORY DATA PORTAL ▾

Please select a survey to export.

- Diagnosis
- Family History
- Medical Care Survey
- General Health
- Referring Organization

Next

Export Data

The following fields are available for you to export data from the datasets assigned to your account and the source of information selected on the previous screen. Select the fields you would like included in your file. Scroll to the bottom of the page and enter a file name. After hitting Submit, you will receive a notification that your export is ready. You may also check the status of your export from the [Manage Export](#) link. If you have any questions, please contact PatientCrossroads at connect@patientcrossroads.com

Options Defined:

- No Option Selected - Export of survey responses for the most recent survey session (regardless of whether the session is incomplete or complete).
- Most Recent Survey - Export of the survey responses for the most recently completed survey session. If no complete survey session exists, then export the most recent incomplete survey session.
- All Completed surveys - Export of the survey responses for all the complete survey sessions, present and past (previously called historical or longitudinal export).
- All Complete and Incomplete Surveys - Export of the survey responses for all complete and incomplete survey sessions, present and past.

<input checked="" type="checkbox"/> Demographics <ul style="list-style-type: none"> <input checked="" type="checkbox"/> _UE_HEALTH_REASON_FOR_REGISTRATION <input checked="" type="checkbox"/> _UE_GENDER <input checked="" type="checkbox"/> _UE_AGE <input checked="" type="checkbox"/> _UE_RACE_(SELECT_ALL_THAT_APPLY) <input checked="" type="checkbox"/> _UE_ETHNICITY <input checked="" type="checkbox"/> _UE_FAMILY_GROUP_CODE <input checked="" type="checkbox"/> _UE_STATE_(USA_ONLY) <input checked="" type="checkbox"/> _UE_COUNTRY 	<input checked="" type="checkbox"/> Questionnaire	Options Defined: <ul style="list-style-type: none"> <input type="radio"/> Most Recent Survey <input type="radio"/> All Completed Surveys <input type="radio"/> All Complete and Incomplete Surveys
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Diagnosis - Page 1

- At what age was the diagnosis made?
- What type of doctor or healthcare provider diagnosed this condition?
- What led to the initial medical evaluation? (Select all that apply.)
- At what age did the participant first begin experiencing symptoms of the condition?
- Which of the following **symptoms** led to the participant's initial medical evaluation? (Select all