

Getting Started Worksheet

* 1. Participant Email Address

2. Name of Patient

3. Date of Birth of Patient

Date

	MM		DD		YYYY
	<input type="text"/>	/	<input type="text"/>	/	<input type="text"/>

4. Name of Applicant

5. Relationship of Applicant to Patient

- Self
- Mother
- Father
- Aunt or uncle
- Grandparent
- Other (please specify)

6. Participant Address

Address

Address 2

City/Town

State/Province

ce

ZIP/Postal

Code

Country

7. Clinical Referral (if applicable)

- Physician
- Geneticist
- Genetic Counselor

Provide their contact information and name of clinic/hospital

8. Laboratory Referral

- Baylor Miraca Genetics Laboratories
- Ambry Genetics Laboratory
- Other (please specify)

9. What is your gender?

- Male
- Female
- Other
- Prefer not to disclose

10. What is your age?

- 17 or younger
- 18-20
- 21-29
- 30-39
- 40-49
- 50-59
- 60 or older

11. What is the highest level of school you have completed or the highest degree you have received?

- Less than high school degree
- High school degree or equivalent (e.g., GED)
- Some college but no degree
- Associate degree
- Bachelor degree
- Graduate degree

12. Which of the following categories best describes your employment status?

- Employed, working 40 or more hours per week
- Employed, working 1-39 hours per week
- Not employed, looking for work
- Not employed, NOT looking for work
- Retired
- Disabled, not able to work

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13. What social media platforms do you have accounts on?

Facebook

Twitter

Instagram

LinkedIn

Google+

Tumblr

Flickr

Pinterest

Path

Vine

Youtube

Redditt

14. How often do you check social media?

More than 20 times a day

Between 10 to 20 times a day

Less than 10 times a day

A few times a week

A few times a month or even less

I don't use social media

15. How many friends do you have on Facebook?

- None
- 1-50
- 51-100
- 101-250
- 251-500
- 501-1000
- 1000-2500
- more than 2500

16. How many followers do you have on Twitter?

- None
- 1-50
- 51-100
- 101-250
- 251-500
- 501-1000
- 1000-2500
- more than 2500

17. How often do you post on social media per week?

- More than 20 times a day
- Between 10 to 20 times a day
- A few times a week
- A few times a month or even less
- I don't use social media

18. How do you share normal updates about your rare disease journey? (Check all that apply)

- Facebook
- Twitter
- Instagram
- LinkedIn
- Google+
- Tumblr
- Flickr
- Pinterest
- Path
- Vine
- Youtube
- Redditt

19. Are you part of a community or group? (Check all that apply)

- Religious/faith
- Cultural
- Career Association
- Volunteer
- Other (please specify)

20. How many times have you created a crowdfunding campaign to raise funds?

- None
- Once or Twice
- Three to five times
- More than 5

21. How many times have you donated to a crowdfunding campaign?

- None
- Once or Twice
- Three to five times
- More than 5

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22. Number of physicians patient has seen

23. Types of physicians patient has seen (Check all that apply)

- Clinical geneticist
- Gastroenterologist
- Cardiologist
- Neurologist
- Endocrinologist
- Pulmonologist
- Psychiatrist
- none
- Other (please specify)

24. Testing done for patient (Check all that apply)

- Comparative Genome Hybridization
- Karyotype / Chromosome analysis
- Gene Sequencing (e.g. single or panel)
- DNA Microarray
- MRI
- Whole Exome or Genome Sequencing
- none
- Other (please specify)

25. Types of support services used for patient (Check all that apply)

- Physical Therapy
- Speech & Language Therapy
- Behavioral Therapy
- Occupational Therapy
- Audiology
- none
- Other (please specify)

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In order to be accepted to this study, a signed consent form must be uploaded and submitted.

[Please click here to take you to the consent form.](#) To scroll down in the form, use your keyboard arrows.