



## Sasha - The Information Seeker

*"In the group, there are women with much more experience than me who can help me."*

### ABOUT

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### DEMOGRAPHICS

**Age:** 36  
**Occupation:** Stay-at-home mom  
**Family:** Married, mother of three children  
**Location:** Austin, Texas

### GOALS

- Round the clock availability of mothers expertise
- Receiving additional information and advice that doctors didn't mention
- Meet moms of children with similar symptoms and learn about care management, what physicians to see, possible tests and medications

### MOTIVATIONS

- Alleviating stress
- Enabling to deal better with the situation
- Feeling empowered in managing her son's needs

### FRUSTRATIONS

- Most support groups are for specific diseases, but where do those go who do not know what the condition is?
- And the few forums that exist for undiagnosed patients are about finding a diagnosis and not about support and advice on how to live in the the current state



## Jennifer - The Tribe Seeker

*"When you talk, you know you're understood."*

### ABOUT

Jennifer's son was a newborn when she got told that he has a health problem. 9 years have passed and they finally received the diagnosis, but the condition is so rare, that it doesn't even have a name, just letters and numbers. Her son requires constant care, so Jennifer quit her job and became the full-time caretaker for him. Most of the time is spent home and Jennifer is lacking social interactions. Unfortunately, she doesn't know any other families that are in a situation like this and her friends and family have a hard time relating to her.

### DEMOGRAPHICS

**Age:** 44  
**Occupation:** Stay-at-home mom  
**Family:** Married, mother of two children  
**Location:** Baltimore, Maryland

### GOALS

- Connecting with women that have also rare and undiagnosed children
- The application has to be safe and respect my family's privacy
- Receive and give emotional support
- Finding friends
- Not be constraint to meet women in local area and instead connect with women around the world

### MOTIVATION TO USE THE PRODUCT

- Reducing feelings of social isolation
- Belonging to a group
- Mental health improvement

### FRUSTRATIONS

- Privacy of her son is of utmost importance for her, and with Facebook's data leaks, she doesn't feel comfortable joining one of their support groups
- Most support groups she found are for rare disease adults and not targeted for parents of rare disease children