To Adults with Prosopagnosia:

Regarding Childhood:

Looking back on your childhood, what strategies did you use that helped you to cope in social environments like a classroom? In particular, we are interested in strategies that you felt were effective, and could be used by other children, regardless of whether or not you knew why you were using those strategies.

Did your friends or family ever do anything, intentional or unintentional, in social situations that helped you identify others? How did this change as you got older?

What strategies were unhelpful, or harmful?

What do you know now that you wish you could have applied growing up?

Social Interactions:

Today, do you find it helpful to tell friends, family, or acquaintances about your disorder? If so, what have you found to be the best way to do it? What do they do to help you in social situations?

Likewise, do you feel that it would have been helpful to be open about Prosopagnosia when you were a child? If so, with everyone or only with certain groups?

Do you feel like others have made any assumptions about you? What, if anything, have you done to address those assumptions?

Over all:

In what ways do you think your disorder has affected you academically? Career-wise?

Have you ever told an employer or potential employer about your prosopagnosia? If not, why not? If so, how did they react? Do you think it impacted you or your career?

If you had the chance to sit down with a child with prosopagnosia, what other tips would you give them? Words of encouragement? Etc.?

What advice would you give to a parent of a child who has prosopagnosia?
To Parents of Children with Prosopagnosia:

Education:

Has your child had difficulties in school as a result of his/her prosopagnosia? If so, what strategies, if any, have you used to address these difficulties?

Has your child been formally diagnosed with prosopagnosia or a similar disorder such as Cortical Visual Impairment? If so, how did you obtain a diagnosis? In what ways has this diagnosis been beneficial or harmful?

What strategies have been implemented in the classroom to help your child adapt at school? Have these strategies been effective?

What have you found to be useful on the teacher’s part? Is there anything you have been able to do to get the teacher "on-board"?

What have you found to be useful when it comes to working with a team of educators (e.g. an Individualized Education Program team)?

If you had the chance to sit down with a parent who has just learned that their child does not recognize faces, what would you say to them? More specifically, what advice would you give them about working with the educational system? What words of encouragement would you offer?
The Difficulty of Diagnosis:

How did you pinpoint your child’s struggle as difficulty with facial recognition specifically?

Do you ever question whether or not your child genuinely has a face recognition disorder?

What tools did you use to determine whether your child has face recognition difficulties?

Have you spoken to your child about prosopagnosia? If so, how did you explain to them? Did it go well? Has the explanation changed as they have gotten older?

Do you face any unique challenges as a parent of a child with prosopagnosia? If so, how have you addressed those challenges?

Have you faced any doubts about how to help your child cope with their face recognition problems? How have you addressed those doubts?

Telling others:

How do others react when you tell them your child has difficulty recognizing faces? How do particular reactions affect you?

Do you have any tricks for telling others about your child's difficulty with faces?

Does your child find it helpful to explain their condition to friends and classmates? If so, in what ways has it helped? If not, why not?

In the home:

Are there any behaviors that you are better able to understand now that you understand the potential motivation behind the behavior?

Do you think your child’s behavior has been influenced by his or her face recognition difficulties? If so, in what ways?

What has helped your child adapt at home?

Looking Back:

What do you wish you had heard from the beginning?
What books have you read that have helped you and your child?

Is there anything else that you would like to share that might be helpful for other parents and their children?