

## Information for Parent's/Caregivers - One Voice Project

### Project Requests

- **We only need the age, first name and country for the child or their siblings.**
- **Please do not include any personal or identifying details.**
- **Parents/Carers are very welcome to use a different first name.**

### Request One

We would very much appreciate it, if affected C/YP were able to answer any of the following questions. They do not need to answer them all, but only as many as they are comfortable with. It can be written in their own writing or dictated to an adult, scanned, typed, or recorded. Please attach to an email.

- How old were you when you got PANS/PANDAS?
- What did it feel like?
- What were the hardest things?
- Who or what helped you?
- How many different doctors have you seen?
- What medicine helped you?
- What did you wish that your doctors knew?
- How was School?
- How did your symptoms affect you in school?
- Have teachers been understanding?
- What would have helped at school?
- What do you wish that your teachers knew?
- What would you say to other children affected by PANS/PANDAS?
- How can we make things better?

### Request Two

We also requesting whether any C/YP or their siblings would like to submit poetry, or related experiences, stories, academic work, artwork and/or any messages about PANS/PANDAS.

We are also hoping to include a letter or extracts from a letter, from C/YP to adults. This could state what adults should know and understand about PANS and PANDAS and what would help. We are sure that the children will have plenty of their own ideas about what to put in their letter. The letter could be to parents, teacher, doctors, or friends for example. It could be a few words or a complete letter as appropriate.

**Please do not send any original copies as we will be unable to return these to you. Please do not include any identifying details for your child apart from their name (real or pseudonym) age and country.**

The information/ resources collected will be then collated and presented in promotional materials including a short YouTube video. This video will be used to raise awareness of the C/YP in PANS/PANDAS for professionals including clinician's and educators.

We are very much looking forwards to hearing the C/YP voice. Thank you very much for taking the time to read this information and for agreeing to participate. We hope that this will be a collaborative and very worthwhile project to support all of our affected C/YP.

**The closing date for contributions is 27<sup>th</sup> September 2021**