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# PARTICIPANT SUPPORTER INFORMATION SHEET

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## Supporting Autistic Participants in Research

### Why Your Role Matters

We recognize that research is most meaningful and inclusive when autistic people can participate in ways that feel comfortable and accessible. Following principles from [AASPIRE](#), we acknowledge that **supporters play an important role** in helping autistic participants:

- By offering assistance when requested, without taking over.
- By helping ensure participants' preferences and needs are respected.
- By reducing barriers so participants can share their experiences fully and authentically.

Your support allows participants to take part in important studies that will help researchers better understand health, stress, and well-being in autistic adolescents and adults.

### What Does Your Role Entail?

- 1) **Virtual Visit 1:**
  - a) If you are supporting someone under the age of 18, we will ask you to be involved in the parental permission/assent process. This entails joining our study's 30 minute consent/screening Zoom call with a research assistant, signing the parental permission form, and supporting the participant in signing the assent form.
  - b) If you are supporting someone 18+, you are welcome to join the visit if the participant requests.
- 2) **Post-Virtual Visit 1:** Participants of all ages will only be eligible to participate after their supporter completes the Vineland-3 screener on their behalf. After Virtual Visit 1, we will e-mail you a link (coming from Pearson) that contains a survey. The survey will ask about the participants' abilities to make sure they are a good fit for this study.
- 3) **Virtual Visit 2:** Participants of all ages will require assistance with the hair sampling process (details below). Supporters are only required for the hair sampling component of Virtual Visit 2, but are welcome to stay for the remaining activities if requested by the participant.

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## Purpose of Hair Sampling

- Hair samples provide a **simple and comfortable way** to measure stress over time.
- Unlike saliva or blood, hair can show **long-term patterns** of stress hormones (cortisol).
- This helps researchers understand how stress and health interact in everyday life, with the goal of improving supports and services for autistic people.

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## What the Procedure Looks Like

The process is designed to be **quick, safe, and minimally disruptive**.

1. **Location**
  - Hair is collected from the **back of the head**, close to the scalp.

- This location is chosen because it is discreet, easy to access, and provides the best sample.
  - 2. **Amount of Hair**
    - About the width of a pencil's lead (a very small lock).
    - The sample is not noticeable once taken.
  - 3. **Steps**
    - The researcher or supporter parts a small section of hair.
    - Hair is cut as close to the scalp as possible (about 1–2 cm).
    - The sample is placed in a labeled foil or envelope for analysis.
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## Overall: How You Can Support the Participant

- **Check In First:** Ask the participant if they want help and how they'd like you to support them.
  - **Provide Comfort:** You can help by sitting close, offering reassurance, or distracting with conversation or a favorite activity.
  - **Assist with Logistics:** If the participant prefers, you may hold hair back, help part the section, or steady their head gently while the researcher cuts the sample.
  - **Respect Boundaries:** If the participant shows discomfort, pause and let them guide the pace. Participation is always voluntary.
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## Overall: Key Principles

- **Respect Autonomy:** Support should help the participant make their own choices—not replace them.
  - **Promote Inclusion:** Your presence ensures the participant has equal opportunity to take part in research.
  - **Value the Contribution:** Every hair sample helps us learn more about autistic health and resilience.
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✓ **Thank you** for supporting participants in this study. Your role makes it possible for autistic voices and experiences to shape research and improve health outcomes.