



Family Participation Agreement

Please carefully read the following guidelines and consent for participation in Claude Moore Precious Time (CMPT):

Participation Information

- Participation in CMPT is voluntary and neither families nor CMPT/James Madison University (JMU) are under contractual obligation to continue receiving/providing services.
- Families may decline to participate or withdraw at any point; however, families do not need to participate continuously to be considered “in” the program.
- The program director will contact enrolled families before each academic semester to determine if they would like to participate in the program for the coming semester. Families may decide to: (A) participate, (B) decline to participate that semester and permit the program director to contact them again the following academic semester, (C) permanently withdraw from the program. Families will be withdrawn from the program if they are unable to be contacted for two consecutive semesters.
- If families decide to permanently withdraw from the program, the program director will cease all participation inquiries, stop sharing family information with the current students (if applicable) and any future students, reassign current students (if applicable), and securely store any family records for (at the least) the minimum time outlined by regulations governing records retention.

Information Regarding Students

- The student respite care provider is not licensed and is not functioning as a Registered Nurse; therefore:
 1. Students cannot administer medications [In the event of a life-threatening allergic reaction, students are permitted to use an epinephrine auto-injector (EpiPen) provided by the family]
 2. Students are not allowed to transport participating family members
- Caregivers are encouraged to engage students in all activities related to the care of their child to the extent that the caregivers are comfortable and students are allowed.
- Some activities related to the child’s care, such as administering feedings to children with special feeding needs, require the caregivers to fill out a special instruction page, which the students will review with the academic director to ensure that they are prepared and understand the procedure(s).
- On the first visit, caregivers must provide the student respite care provider with instructions and demonstrations regarding their child’s special needs and equipment.
- If caregivers are to leave the house during respite care hours, they must leave an emergency phone number and instructions in the event of an emergency.

Assumption of Risk

In determining whether your child will participate in this program, you should be aware that JMU, the College of Health and Behavioral Studies (CHBS), the Institute for Innovation in Health and Human Services (IIHHS), the School of Nursing (SON), and CMPT cannot undertake financial or legal responsibility for your child(ren) in the event that your child(ren) is injured, becomes ill or harmed while participating.

Information Sharing

At the beginning of the semester, CMPT will share the following family information (provided to CMPT by the family) with the specific student respite care providers matched with the family:

- Children's names, birthdates and diagnoses/health problems
- Contact information: phone numbers, addresses, email addresses for the family, etc.
- Information related to the child's care including: allergies, special diet, etc.
- Any other information disclosed by the family to CMPT as relevant.

CMPT will only share this information with the specific students matched with the family each semester. This information will be stored on a secure server requiring special permission for access. Students will be provided a hard copy of the family's contact information (phone numbers, addresses, email addresses, etc.) but students will not be permitted to possess physical records of information regarding the children's health information and care. Students may receive a digital copy of the children's health records for future reference as needed. Families may revoke this permission at any point by contacting the program director.

If a family revokes this permission, CMPT will immediately stop sharing family information with the current students (if applicable) and any future students. This information will be securely stored for (at the least) the minimum time outlined by regulations governing records retention. Families who revoke permission to share information will no longer be considered eligible to participate in the program.

By signing this document below, I certify that:

1. I have read and understand the guidelines of Claude Moore Precious Time
2. I specifically and completely release, hold harmless, and indemnify James Madison University, the College of Health and Behavioral Studies, the Institute for Innovation in Health and Human Services, the School of Nursing, Claude Moore Precious Time, and the individual employees and students from all liability, including negligence, and other causes of action, debts, claims, and demands of every kind which I have now or which may arise out of or in connection with my participation in this program.
3. I consent for Claude Moore Precious Time to share the information identified above until I withdraw from the program, or rescind this permission by contacting the program director.

Child(ren)'s name(s): _____

Parent/guardian/caregiver's name: _____

Parent/guardian/caregiver's signature: _____ Date: _____

Optional participation in research study

Identification of Investigators & Purpose of Study

You are being asked to participate in a research study conducted by JoLynne Bartley, Hyuntae Kim, and Julianne Secrist from James Madison University (JMU). The purpose of this study is to understand how you use the services provided by Claude Moore Precious Time (CMPT). Specifically, we are interested in understanding the effectiveness of our program in improving family caregiver wellness and educating JMU health and human service students about children with special healthcare needs (CSHCN). This study will contribute to the evaluation of the effectiveness of the CMPT program and identify areas for improvement for the program.

Research Procedures

The purpose of this consent form is to ensure that your evaluations, feedback, and experiences as a caregiver can be used for research purposes, program evaluation, quality improvement, or other related activities conducted by JMU's Claude Moore Precious Time.

By signing this consent form, you agree that any evaluations, feedback, or other information provided by you in the course of your involvement with JMU's Claude Moore Precious Time may be used for research or other purposes as described above.

This study consists of an online survey that will be administered to individual participants through Qualtrics. You will be asked to provide answers to a series of questions related to your experiences with CMPT and navigating daily life.

Time Required

Participation in this study will require approximately 10 minutes of your time.

Risks

The investigators do not perceive more than minimal risks from your involvement in this study (that is, no risks beyond the risks associated with everyday life).

Benefits

Possible direct benefits from participating in this study include improvements to the CMPT program that can impact your experience in the program. Potential benefits to the CMPT program include providing feedback to improve the program in the future. Therefore, information from this survey may benefit CMPT families, JMU students, and the program now and in the future. You will not receive any compensation for participation in this study.

Confidentiality

The results of this research will be presented at internal meetings, at national and/or international conferences, and published in the scholarly literature. While individual responses are obtained and recorded online through Qualtrics, data is kept in the strictest confidence. Your responses will be linked to your identity and coded to maintain confidence. Aggregate data will be presented representing averages or generalizations about the responses as a

whole. All data will be stored in a secure location accessible only to the researchers. Final aggregate results will be made available to participants upon request.

Participation & Withdrawal

Your participation is entirely voluntary. You are free to choose not to participate. Should you choose to participate, you can withdraw at any time without consequences of any kind. Your decision to participate or withdraw will not affect your services from CMPT.

Questions about the Study

If you have questions or concerns during the time of your participation in this study, or after its completion or you would like to receive a copy of the final aggregate results of this study, please contact:

JoLynne Bartley
Institute for Innovation in Health and Human Services
James Madison University
bartl2jx@jmu.edu
(540) 568-4113

Hyuntae Kim
Institute for Innovation in Health and Human Services
James Madison University
kim58hx@jmu.edu
(540) 568-3280

Julianne Secrist
School of Nursing
James Madison University
secrisjj@jmu.edu
(540) 568-8903

Questions about Your Rights as a Research Subject

Dr. Lindsey Harvell-Bowman
Chair, Institutional Review Board
James Madison University
(540) 568-7308
harve2la@jmu.edu

Giving of Consent

I have read this consent form and I understand what is being requested of me as a participant in this study. I freely consent to participate. The investigators provided me with a copy of this form through email. I certify that I am at least 18 years of age. By signing below, I am consenting to participate in this research.

Jolynne Bartley

Name of Researcher (Printed) Date

Hyuntae Kim

Name of Researcher (Printed) Date

Julianne Secrist

Name of Researcher (Printed) Date

This study has been approved by the IRB, protocol #IRB-FY25-6.

Your Signature_____ Date_____

Your Name (printed)_____