**Frequently Asked Questions**

**What is Project WellCAST?**

Project WellCAST is a research study that focuses on how to best support caregivers of children with rare disorders remotely. This study is currently funded by the National Institutes of Health. Although all Project WellCAST activities occur virtually, our study team is primarily housed at Purdue University, with additional investigators and clinicians located across the world! Together, our goal is to understand how to best match rare disorder families with evidence-based supports and treatments that will help their families live happy, healthy lives.

**What is the goal of Project WellCAST?**

Our goal is to understand how to best support rare disorder caregivers in their day-to-day lives. To do this, we are conducting a research study that evaluates the helpfulness of several different types of support programs. We want to learn which programs are most helpful for rare disorder caregivers. We also want to learn which treatments are the best fit for different caregivers based on their experiences, identities, and lifestyles.

**What does participation entail?**

Participation spans several steps:

First, participants complete a **screening process** to determine whether they are eligible for the study. This process includes a short web-based questionnaire and a phone interview with a member of our team.

Second, participants who are eligible and consent to join the study complete a variety of **questionnaires** about their feelings and experiences. They also complete **brief snapshot surveys** that are “pinged” to their phone three times a day for two weeks. These snapshot surveys help us learn about participants’ daily lives, including their feelings and experiences.

Third, participants are assigned to **receive support or, alternatively, join a waitlist to receive support during the next cycle.** Participants on the waitlist are invited to continue participating in study questionnaires until the next cycle starts, allowing us to understand how caregivers’ lives and experiences change when they are not accessing our supports and treatments. This is called a “waitlist control.”

Fourth, participants matched to a support program are **assigned to one of several support programs**. Because this is a research study, participants cannot select which type of support they receive. However, participants will be provided substantial information about their assigned treatment and asked to provide consent to participate in the treatment before moving forward.

**What types of resources might I receive?**

The types of treatment and/or support participants receive may include one or more of the following programs:

1. ***Self-guided resources*** that focus on a variety of topics such as challenging behavior, communication, caregiver well-being, and community support.
2. ***Evidence-based mental health treatment***. Here, caregivers will receive an evidence-based treatment in either an individual or group format. All treatments are provided by highly qualified clinicians who are supervised by licensed psychologists. Examples of treatment include Acceptance and Commitment Therapy, Dialectical Behavioral Therapy, or Culturally Informed Cognitive Behavioral Therapy.
3. ***Evidence-based treatment parent-mediated child behavior training*** to support your child’scommunication, challenging behavior, or sleep. These parenting-oriented therapies are evidence-based, delivered by skilled clinicians who are supervised by licensed behavioral interventionists, and are deployed in individual or group formats.
4. ***Peer-to-peer coaching,*** provided by rare disorder caregivers. Here, peer coaches help identify and overcome barriers that might interfere with treatment.
5. Finally, although Project WellCAST is open to people of all races and ethnicities, we have funding to provide additional ***support groups for Black rare disorder caregivers***. These groups focus on race-related experiences and are facilitated by Black therapists. Any Black caregiver is eligible to participate in these support groups, regardless of the other types of support they receive as part of Project WellCAST.

**Can I choose which treatment or support I receive?**

In short, no. Because this is a research study, **caregivers cannot sign up for a specific type of therapy**. However, during the screening process, we *will* ask what types and formats of therapy you are not comfortable completing and will never make you do anything you do not want to do. At any point in the study, you can always stop participating in WellCAST at any time, without penalty.

**How will I give you feedback about my experience?**

Great question! Feedback is very important to us. You will provide data throughout the study to help us learn about you, your family, and your experiences in WellCAST.

First, we will use web-based forms to collect information about your past experiences, family demographics, relevant health and medical information, and perspectives and feelings. Throughout the study, we will ask you to repeat some of these forms so that we can see how your experiences and feelings change over time.

We will also collect data using “snapshot surveys” that are sent to your smartphone. On each day that you are in the study, we will send brief “pings” to your phone that will ask questions about your daily life. Questions might ask what you’re currently up to, your current stress and mood, and how you slept. These questions are much shorter than typical forms – typically only taking 1-3 minutes to complete – and help us learn about the many changes that happen across your daily life. We use these surveys because we know that life changes quickly, particularly for rare disorder caregivers! We want to learn about the “highs and the lows” as you experience them in your daily life.

**What do I gain?**

Although we hope that participation will support caregiver well-being, Project WellCAST does not provide any guaranteed benefit to participants. By participating in WellCAST, it is possible that you are helping generate knowledge that will improve support options for rare disorder caregivers. Our goal is to use the data that we collect to understand what supports are best for whom, and how to best tailor the treatments to the pieces that make each rare disorder caregiver unique.

**Is participation free?**

Yes, all resources and treatments are provided to participants free of charge, and we provide up to $100 compensation for the time caregivers spend completing questionnaires. If your assigned treatment requires the use of technology or materials, we send everything to you free of charge. You are not responsible for any lost or damaged equipment, and we prepay shipping for you to send materials back to us. We can also provide technology to borrow and Wi-Fi hotspots if you need them, free of charge.

**What are some risks?**

Any clinical trial comes with some risks. The risks for Project WellCAST vary depending on the type of support you receive, and these risks will be clearly shared with you prior to you providing consent to participate in your assigned support activities. In general, though, we always remind folks that seeking support, participating in treatment, and answering questions about your mood and well-being can bring up challenging emotions and feelings. Caregivers attempting to change how they engage with their child may also experience frustration, including from their child. Please know that if a support option isn’t right for you, you can stop the study at any time, without penalty.

Any research study also includes risks related to technology and data, including breaches in confidentiality. Again, these risks will be clearly shared with you as part of the informed consent process. We will also share how we have carefully designed our study to minimize theses risks.

Please know that we take your confidentiality very seriously. All of your study data are labeled with a numeric ID rather than your name, we store and transfer all data using secure software programs and platforms. If you participate in a group- or peer-to-peer support option, all participants will also receive training on confidentiality and respecting each other's privacy, although we cannot guarantee that these rules will be upheld by all participants. These risks and how we protect you from risk will be talked about further as part of the consent process.

**How do I enroll?**

If you’re interested in joining WellCAST, the first step is to fill out the study prescreening form to see if your family matches our eligibility criteria. We will send you a link to this form when you e-mail **wellcast@purdue.edu**.

Once you receive the link, you can complete the screening forms and also sign up for a brief phone call during which we will describe the project and complete a few more screening questions. This call takes no more than 30 minutes. Shortly after this call, you will receive notification of whether you are invited to participate in the current round of WellCAST, at which point we will start the consent process.

**What if I have questions?**

We have provided you with a lot of information, and it’s important to us that you feel like you fully understand WellCAST. If you have any additional questions, please let us know by emailing wellcast@purdue.edu.

Thank you for your time and interest in being part of the Project WellCAST community. We look forward to hearing from you soon!