



The Wiedemann-Steiner Syndrome Foundation (WSSF) believes that lack of research presents the biggest barrier to care for patients. We aim to expedite the exploration of key issues and facilitate research that can improve both patient care and medical practice. In an ongoing survey, ([see here](#) if you wish to contribute!), an initial 48 respondents described several symptoms as being of “Very High Impact,” on the daily quality of life of the patient. We consider these to be the current priorities of the patients and their families:

- Disruptive behaviors (including aggressive behaviors, impulsivity, behaviors outside of age-appropriate societal norms)
- Digestive system issues (including constipation or vomiting)
- Intellectual Disability
- Feeding difficulties
- Attention Issues
- Communication issues (including limited speech and language understanding)

Additionally, the following are the top 4 most impactful symptoms by age group

- Less than 9 years old
 - Feeding difficulties
 - Communication issues (including limited speech and language understanding)
 - Digestive system issues (including constipation or vomiting)
 - Growth issues (including poor growth and short stature)
- 10 to 17 years old
 - Anxiety
 - Disruptive behaviors (including aggressive behaviors, impulsivity, behaviors outside of age-appropriate societal norms)
 - Digestive system issues (including constipation or vomiting)
 - Difficulty making friends
- 18 years and older
 - Anxiety
 - Disruptive behaviors (including aggressive behaviors, impulsivity, behaviors outside of age-appropriate societal norms)
 - Digestive System Issues (including constipation or vomiting)
 - Difficulty making friends

We consider the symptoms listed above to be the current priorities of the patients and their families. This list is current as of October 2024. As we receive additional responses to this survey, we will update this list.

AWARD PROCESS

Applications will be accepted on a rolling basis via Google Form a [grant \(with a \\$30,000 budget limit\)](#). Grants will have a maximum duration of one year from project start date. Applicants should only request what is needed as funds are limited.

PROJECT CRITERIA

- Involve Wiedemann-Steiner Syndrome
- Directly impact patient care for one or more patients
- Scientifically valid and feasible
- Research ethics board approval, where applicable
- Studies that involve collaborations between more than one research institution will receive special consideration

APPLICATION REQUIREMENTS

Research proposals must include:

- How the study will improve care
- Scientific summary containing background, hypothesis, methods
- Budget justification and timeline
- Lay summary addressing a non-medical, non-scientific audience
- Additional sources of funding and rationale for requesting a grant from this program

REVIEW AND SELECTION PROCESS

Applications will be reviewed by both the scientific advisors and parent (lay) board members of the Wiedemann-Steiner Syndrome Foundation for their impact on care, scientific merit, and relevance to the priorities of patients and their families. Upon submission of your application, you can expect a response via email within 45 days.

Please contact Helen Hernandez at helen@wssfoundation.org with any questions.

REPORTING GUIDELINES

- Grantees are required to submit a final report at the completion of the award (12 months) summarizing major activities and research findings, with a lay summary outlining how their work improves patient care.
- An oral presentation to parents is required, with options to join the WSSF annual conference or present through online video-conference.
- Funded projects are expected to lead to dissemination of results through publication, meeting presentation, and/or generate preliminary data for larger studies directed at improving patient care.
- Grantees will notify the WSSF if other grants are received as a result of grant funding.
- Grantees will acknowledge the WSSF in publications resulting from grant support and will notify the WSSF when such papers have been submitted.
- WSSF will seek non-exclusive permission to publish final reports and/or published research results on the Foundation's website.

APPLICATION FORMAT

Applications should be submitted via Google Forms: [Grant \(\\$30,000\)](#)