Roadmap to build capacity for patient-centered clinical comparative effectiveness research for SLC13A5 Epilepsy.

TESS Research Foundation developed this research roadmap to build capacity for patient-centered clinical comparative effectiveness research (CER) for the ultra-rare disease SLC13A5 Epilepsy. This roadmap is driven by the patient-voice and encompasses guidance from multiple partners, including patients, clinicians, industry partners, government officials, and academic partners. The figure below encompasses our overall strategy.

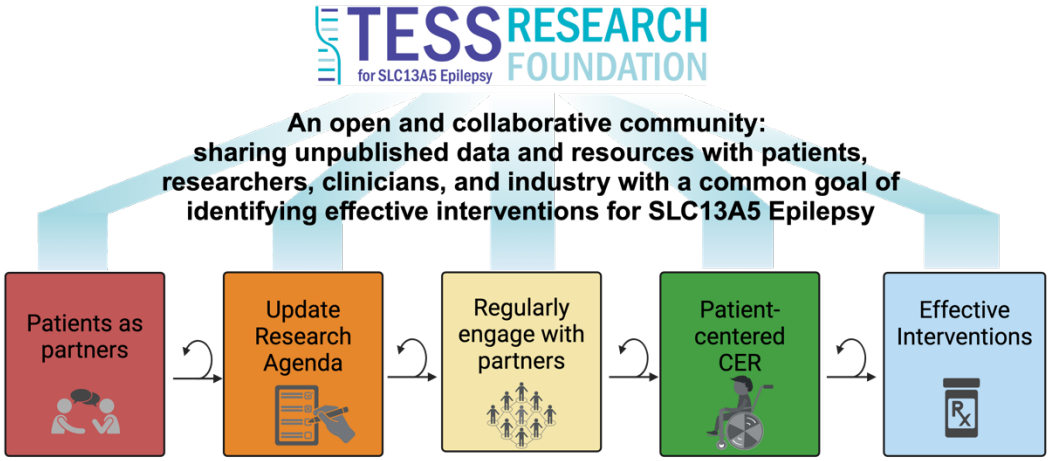

Figure 1 Roadmap to build capacity for patient-centered CER. As the only organization in the world dedicated to SLC13A5 Epilepsy, TESS Research Foundation is uniquely suited to bring all partners together to develop a unified research roadmap with a clear goal: identify interventions for SLC13A5 Epilepsy.

This project was partially funded through a Patient- Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award EASO-30273. The views presented in this report are solely the responsibility of the author(s) and do not necessarily represent the views of PCORI®.

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KEY TERMS AND DEFINITIONS

SLC13A5 Epilepsy: a genetic disease caused by bi-allelic variants in the SLC13A5 gene that causes a severe epilepsy, global developmental delay, a severe movement disorder, tooth abnormalities. This is also known as: SLC13A5 citrate transporter disorder, DEE25, SLC13A5 Deficiency.

Patient-centered clinical comparative effectiveness research: assessing two or more different healthcare options to understand what works best for different people in different circumstances.

Patient: Someone affected by SLC13A5 Epilepsy. At times, this may also refer to a patient's family.

Researcher: An individual addressing research questions in an academic, clinical, or industry setting.

Clinician: An individual who provides care for patients. Among others, this includes doctors, physical therapists, occupational therapists, clinical geneticists, dentists, and others in the healthcare setting

Industry partner: a for-profit entity that participates in research and/or drug development.

BACKGROUND

TESS Research Foundation (TESS) is the only non-profit in the world driving patient-centered research and supporting families affected by SLC13A5 Epilepsy. Since our founding in 2015, we have made significant progress in our mission: driving cutting-edge research to diagnose, treat, and ultimately cure SLC13A5 Epilepsy, while providing support for affected children and their families.

As a non-profit, TESS is uniquely suited to bring all partners together with a common goal: identify effective interventions for the SLC13A5 Epilepsy community. Throughout 2024, TESS developed an updated, patient-centered research agenda and built the capacity for patient-centered CER. We built a strong community centered around the patient voice, with a group of invested partners including academic researchers, clinicians, industry partners, patient advocates, and government officials. This document focuses on sharing this research agenda with all partners and identifying how TESS will use the research agenda to achieve our long-term goals.

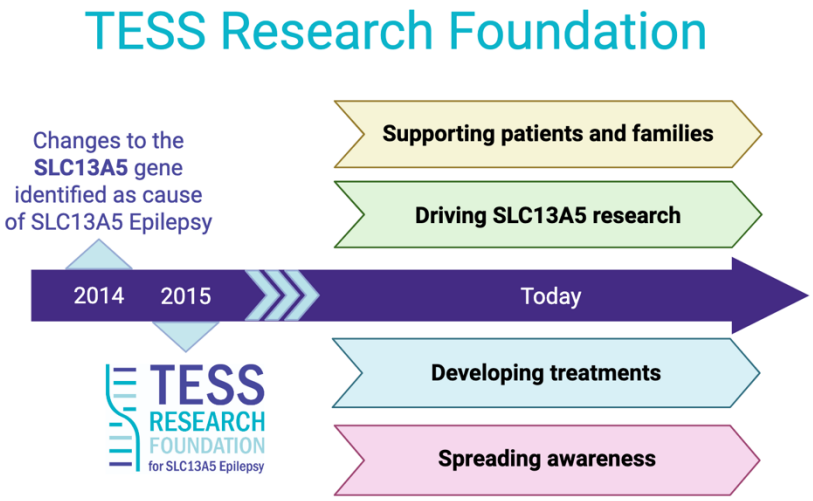

Figure 2 TESS Research Foundation was founded in 2015 and has been making progress ever since.

Our research agenda will facilitate the SLC13A5 community transitioning from identifying the most relevant CER to actively engaging in CER. While our understanding of SLC13A5 is continually evolving, our community is invested in using this foundation as a launching point for patient-centered CER.

A rare disease with significant need

SLC13A5 Epilepsy is a rare, pediatric epilepsy identified by the frequent intractable seizures that start shortly after birth. The disease is caused by pathogenic variants in the SLC13A5 gene which codes for a sodium-dependent citrate transporter, NaCT, which moves citrate – a key metabolite involved in energy production– from outside the cell into the cell. In addition to the intractable seizures, there are additional symptoms including movement disorders and global developmental delays that present throughout child- and adulthood. SLC13A5 Epilepsy impacts whole families– affected patients require 24-hour care, as they have trouble walking, eating, and sleeping. Individuals with SLC13A5

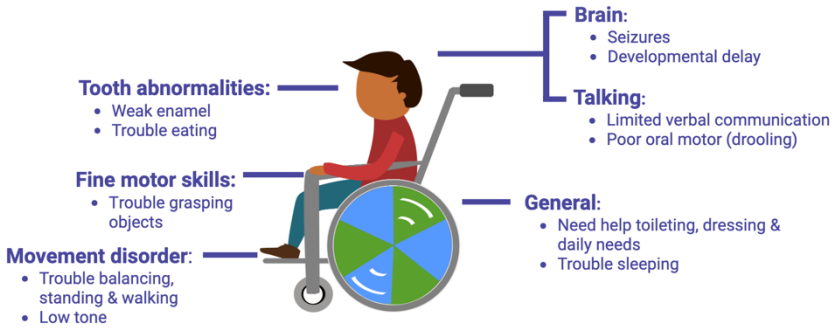

Figure 3 SLC13A5 Epilepsy is a disease that affects many different areas of the body.

Epilepsy also have limited expressive language, low tone, and tooth abnormalities (Fig. 1)[1–4,6]. Patients need help bathing, toileting, and dressing, further highlighting the impact on the whole family. Currently, there are no targeted treatments for this disorder, only symptomatic management.

We have heard from affected families: there is a significant and urgent need for rapid, patient-centered research to determine the most effective interventions for SLC13A5 Epilepsy. This research agenda builds the infrastructure for patient- centered CER to identify the most effective interventions for the patient community who needs treatments now.

Relevant questions that need to be addressed with testable hypotheses and meticulous studies include the following

- Will my loved one walk?
- Why is there such a severe movement disorder? What does this look like over time?
- Will my loved one talk?
- What is the best adaptive communication device to use?
- What are the most effective therapies to help my loved one walk?
- How much can my loved one understand what is going on around him/her?
- What is the most effective anti-seizure medication?
- Why do some affected individuals have seizure control and some don't?
- Are there other diseases that are similar to SLC13A5 Epilepsy?
- I am carrier with one SLC13A5 variant, will this have any negative impact on me?
- Will my loved one have behavior issues as s/he grows up?
- Is there a currently approved treatment for another disease that could help with SLC13A5 Epilepsy?
- How can we come together to develop new treatments?
- Why do multiple affected siblings in the same family have different clinical presentations?
- Why are there tooth issues?
- What is the best method to receive a diagnosis?
- Will eating foods with citrate impact the severity of this disease?
- Who should be a part of my loved one's care team?
- What will this disease look like as my loved one grows up?
- At what age will treatments be effective?
- How will this diagnosis impact family planning for myself and my children?
- How common is SLC13A5 Epilepsy?

CURRENT LANDSCAPE

Current gaps limiting capacity to engage in patient-centered CER

As a newly identified, ultra-rare disease, there are some critical factors missing to identify the most promising treatments for SLC13A5 Epilepsy:

- There is limited knowledge regarding the natural history of SLC13A5 Epilepsy.
- There are currently no targeted treatments for SLC13A5 Epilepsy, only symptom management.
- There are limited preclinical models available to identify new interventions for SLC13A5 Epilepsy.
- As an ultra-rare disorder, there is a limited number of affected patients.

We must be cognizant of what we ask of our patient community, always balancing the need to have the patient-voice drive our efforts and reducing the burden we put upon our patient families. These gaps and challenges highlight the need to build capacity for the SLC13A5 community to move towards patient-centered CER.

While there are gaps that need addressing to move the SLC13A5 community closer to patient-centered CER, it is also important to acknowledge how the landscape has changed over the past 10 years since the founding of TESS Research Foundation. The community is organized with a patient registry, ongoing studies, many more models and biobanks, and there have been multiple research conferences. These changes are a significant reason why TESS Research Foundation worked with our partners to build our patient-centered research agenda, an important step that lays the groundwork for patient-centered CER.

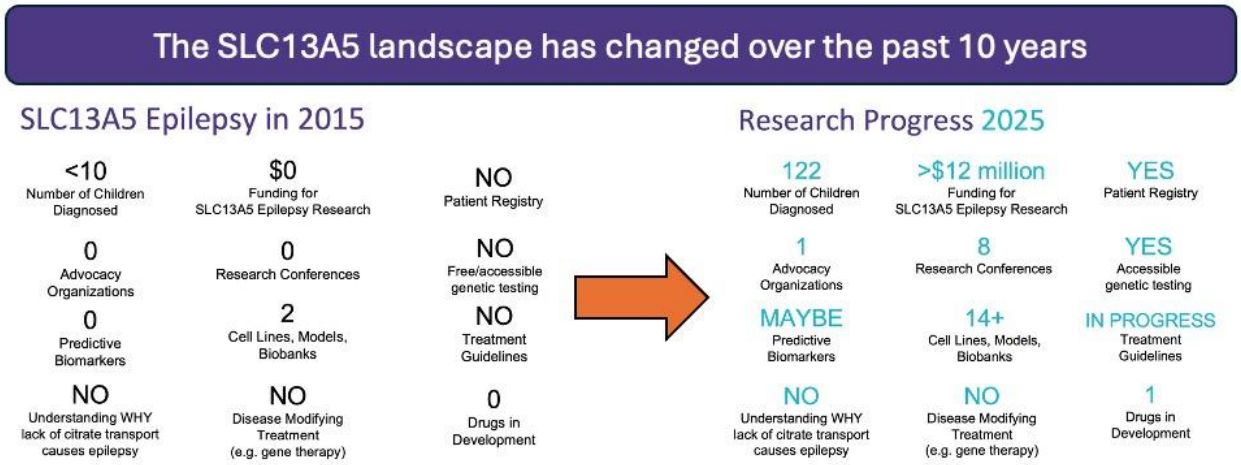

Figure 4 The SLC13A5 landscape has changed and our community is primed to build capacity for patient-centered CER.

Research is moving rapidly

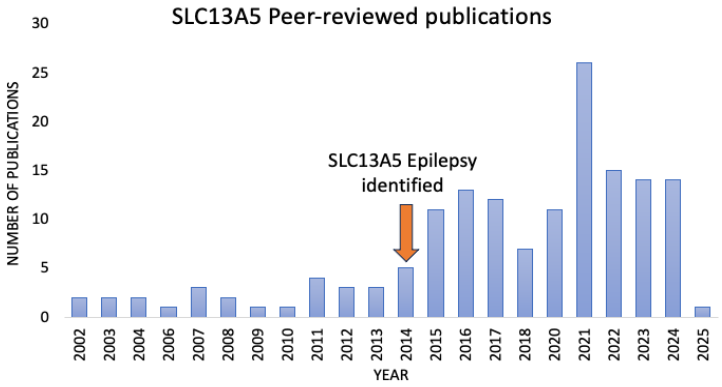

Figure 5 There has been a significant increase in SLC13A5 related publications since the identification of SLC13A5 Epilepsy.

There has been an uptick in SLC13A5 peer-reviewed publications since the identification of SLC13A5 Epilepsy and TESS Research Foundation. This reflects the impressive progress of the research community, and TESS Research Foundation plays an important role in this as well. TESS staff co-author publications about SLC13A5 Epilepsy, reflecting TESS' ability to collaborate with both the research community and affected communities. While this recent increase in SLC13A5 peer-reviewed publications demonstrates significant progress and a changing research landscape (Fig. 3), affected patients are suffering and the SLC13A5 Epilepsy community continues to face significant barriers for effective treatments and improved quality of life[5,7,8].

SLC13A5 Epilepsy is arguably a "simple" genetic puzzle—a monogenic, inherited, loss-of-function disease caused by changes to the SLC13A5 gene and loss of citrate transport—but we still have limited understanding as to the role of citrate and why a lack of citrate transport causes such a devastating disease.

In the next 10 years, we predict the SLC13A5 community will accomplish much more.

A natural history study establishes basic understanding of SLC13A5 Epilepsy

A foundational question facing the SLC13A5 Epilepsy community is: what are the most effective treatments and interventions available to patients? To answer this question, we will use information published from the ongoing SLC13A5 Epilepsy Natural History Study. TESS has sponsored and partnered with three academic medical centers on SLC13A5 Epilepsy. This non-intervention study, led by Brenda Porter, MD, PhD, has collected a significant volume of data. These data are the result of a multi-year, multi-site at Stanford University (PI Dr. Brenda Porter), Brown University (PI Dr. Judy Liu) and UT Southwestern (PI Dr. Kimberly Goodspeed), in partnership with TESS Research Foundation.

The data associated with this study include the following: spectrum of disease, phenotype across the age spectrum, antiseizure medication usage, quality of life measurements, biomarker discovery for future clinical trials. Portions of these studies have already been published.[7,9,10] They identify current treatments used by SLC13A5 Epilepsy patients and lay the foundation to determine the most effective treatment and

interventions currently available, as well as treatments that will be specific for SLC13A5 Epilepsy. We will use this information as we determine how to best address relevant CER for SLC13A5 Epilepsy.

A need to grow our SLC13A5 community

Our natural history study is an important step towards understanding SLC13A5 Epilepsy and building capacity for patient-centered CER. Additionally, we must bring all partners together to continue learning and listening to the patient and family community. This includes bringing all partners together to build trust, keep the patient-voice driving our actions, and identify promising strategies to move towards patient-centered CER. This involves bringing together our current community of patients, researchers, clinicians and industry partners. Additionally, we must bring in other partners who we have not effectively engaged with yet. This includes payers, regulatory officials, and policy makers.

GOALS AND OUTCOMES

Throughout the following five years, we will use our updated SLC13A5 Research Agenda to achieve the following goals and outcomes:

We aim to achieve the following goals:

- The needs of the SLC13A5 patient community drive capacity for patient-centered CER
- Identify promising interventions for SLC13A5 Epilepsy
- Build a collaborative community where all partners have a firm understanding of the needs of the SLC13A5 Epilepsy patient community

Table 1 Summary of outcomes moving towards patient-centered CER

	Summary of outcomes
Outcomes: 2025-2028	• A renewed, open, and trustworthy network in the SLC13A5 community continues to meet regularly • New collaborations between TESS and 5 academic labs, 1 industry partner, and 5 clinicians • Identify working groups that meet regularly to identify promising strategies to address patient-centered CER • Identify promising strategies to engage the SLC13A5 Epilepsy community in CER
Outcomes: 2029 and beyond	• Identify promising interventions to address the needs of the SLC13A5 Epilepsy community • 5 peer-reviewed publications that include patients, advocates, TESS as authors or listed in acknowledgements • 3 projects that directly address the patient-centered CER established • Share all resources with the rare disease community

Our updated research agenda will act as the foundation to achieve these goals. The research agenda identifies top clinical research needs, preclinical research needs focused on translational research, as well as the required infrastructure to continue building towards patient-centered CER. Our goals emphasize a key area of need: continuing to nurture and support the SLC13A5 community. This is instrumental to achieving our other goals and ensuring that all partners are focused on the needs of our patient community. In order to identify promising interventions to address the needs of the SLC13A5 Epilepsy community, we need to continue building trusting relationships with all partners.

AN UPDATED RESEARCH AGENDA: BUILDING THE INFRASTRUCTURE FOR PATIENT-CENTERED CER

To build our updated, patient-centered research agenda for the SLC13A5 Epilepsy community, we listened to the SLC13A5 community (Fig. 4). This agenda was developed by surveying the patient community to identify what was important to patients and their families. Since a majority of the patient population are children and non-verbal, we asked caregivers to share what is important to the affected community. We also surveyed the research community to identify specific research themes and priorities.

TESS Research Foundation assessed, summarized and drafted the initial research agenda based on these responses and under the guidance of the Project Advisory Committee (PAC), revised, ranked, and finalized the research agenda (Fig. 4).

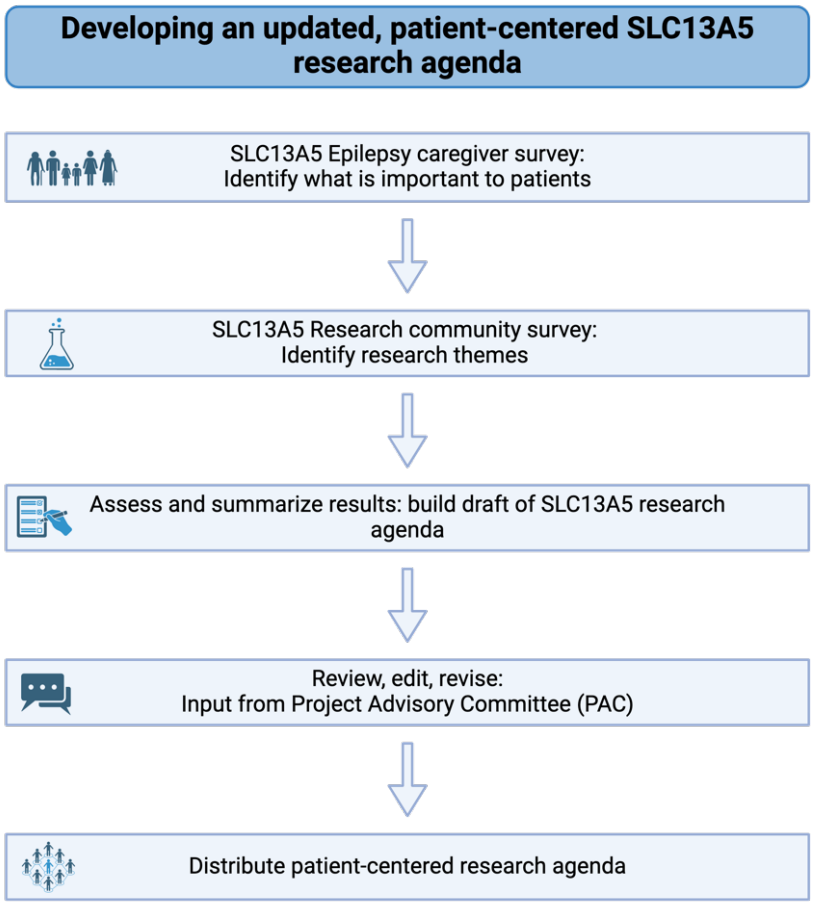

Figure 6 Many partners contributed to our updated, patient-centered SLC13A5 research agenda.

The PAC is comprised of multiple partners in the SLC13A5 community. While some PAC members fill multiple roles, we put their primary affiliation below:

- 4 lived experience experts (family members)
- 2 clinicians
- 2 industry members
- 1 academic researcher
- 1 TESS Science Advisory Board member
- 1 current NIH program officers
- 1 retired NIH division lead

One of the key takeaways from our family community was identifying top symptoms to address. The top three (3) symptoms were:

- epilepsy (seizures)
- communication
- movement.

The priorities of the community changed with the age of the affected patient, reflecting the need to listen to a diverse group of affected families to accurately understand how SLC13A5 Epilepsy changes with age (Fig. 5).

This information is fundamental as we move towards patient-centered CER because it suggests that the most appropriate interventions may change as patients develop. This is also a key piece of information because it is learning directly from our patient community about what is important to patients and families.

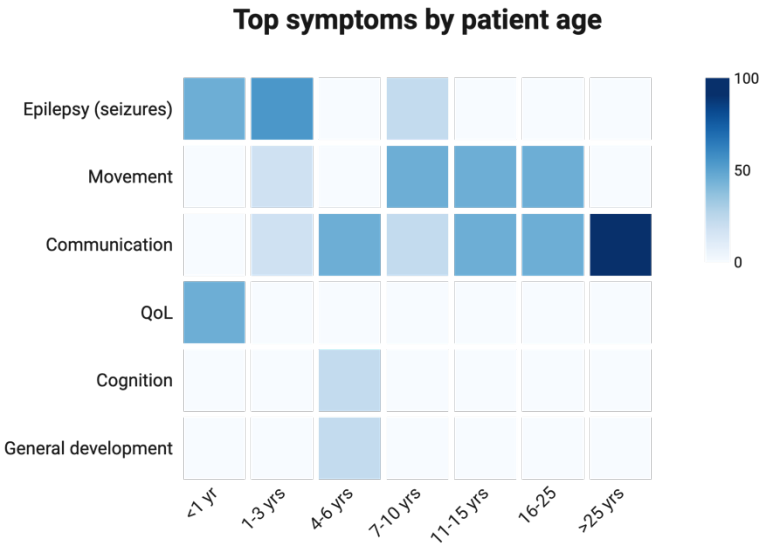

Figure 7 Top symptoms across the lifespan.

Clinical research priorities

The table below outlines the Clinical portion of the SLC13A5 Research Agenda. These ranked priorities reflect the most critical needs of the SLC13A5 community. It is important to note that although these are ranked, the lowest ranked themes and priorities still reflect significant needs required to move our community to patient-centered CER.

Table 2 Clinical research needs

Theme	**Specific research priority**
1. Developing new therapies	1. Progressing gene therapy to clinical trial 2. Identifying disease-modifying therapies 3. Identifying a curative drug
Developing new therapies will build infrastructure for the following patient-centered CER: ● *Which therapy is most effective at treating seizures?* ● *Which therapy is most effective at treating the movement disorder?* ● *Which therapy will improve verbal communication?*	
2. Identifying drug targets	1. Determining disease mechanism 2. Developing treatment for citrate pathology 3. Drug repurposing 4. Identifying downstream pathways for drug development 5. Delivering large molecule therapies to appropriate tissue
Identifying drug targets will build infrastructure for the following patient-centered CER: ● *Are there currently FDA-approved drugs that could address specific symptoms of SLC13A5 Epilepsy?*	
3. Natural History Study: learning about SLC13A5 Epilepsy	1. Developing metrics to use in clinical trials 2. Defining non-seizure outcomes (movement phenotype, communication, cognitive impact) 3. Studying disease spectrum 4. Researching to help improve Quality of Life 5. Continuing NHS of SLC13A5 Epilepsy 6. Continuing NHS with heterozygous carriers
The natural history study will build infrastructure for the following patient-centered CER: ● *What are the best therapies (occupational, physical, etc.) to support SLC13A5 patients?* ● *What interventions can support families affected by SLC13A5 Epilepsy?* ● *What therapies are most effective at different ages? (newborn, childhood, adult?)* ● *What are the best ways to support patients as they participate in clinical trials?*	
4. Developing treatment guidelines	1. Studying the impact of early and effective treatment 2. Determining the impact on Quality of Life 3. Developing clinical treatment guidelines

Developing treatment guidelines will build infrastructure for the following patient-centered CER: ● *When is the best time to start treatment for SLC3A5 Epilepsy?* ● *Who should be included in SLC13A5 Epilepsy patient care?*	
5. Currently available treatments: seizures	1. Identifying seizure medications 2. Identifying immediate treatments 3. Determining medication dose and age
Determining currently available treatments for seizures will build infrastructure for the following patient-centered CER: ● *What are the most effective anti-seizure medication dose for different ages? (newborn, childhood, adulthood?)* ● *What is the most effective combination of anti-seizure medications?*	
6. Understanding genetics	1. Characterizing genetic variants 2. Including SLC13A5 on gene panels 3. Determining incidence and prevalence (particularly identifying misdiagnosed or undiagnosed patients)
Understanding genetics will build the infrastructure for the following patient-centered CER: ● *What is the best genetic testing method for diagnosis?*	
7. Expanding education and awareness	1. Educating clinicians about SLC13A5 Epilepsy 2. Increasing collaboration amongst researchers, clinicians, advocacy groups 3. Access to TESS resources and knowledge base
Expanding education and awareness will build infrastructure for the following patient-centered CER: ● *What is the best way to engage with patients throughout the research process?* ● *What is the most effective method to communicate research progress with the SLC13A5 Epilepsy patient community?*	

Preclinical research priorities

The preclinical research portion of the research agenda are shown in the table below. In general, the preclinical portion of the research agenda is focused on translational research that will lay the groundwork for developing therapeutics for SLC13A5 Epilepsy. We will build models and therapeutics that target areas that are important to affected families.

Table 3 Preclinical research needs

SLC13A5 Epilepsy: Pre-clinical research priorities	
1. SLC13A5 biology	1. What is the role of SLC13A5 throughout development and disease? 1. What are the biochemical and biological functions of SLC13A5?
Building infrastructure for patient-centered CER by: ● *Understanding the mechanism of disease and laying the groundwork for developing new therapeutics.*	
2. Therapeutic development	1. Can we develop small molecules to modulate SLC13A5/NaCT function? (especially activators) 2. At what stage of development can we reverse the consequences of disease? 3. Will ER stress and/or unfolded protein response affect gene therapy and/or additional treatments? 4. Can drugs target specific groups of variants? 5. Can targeting the liver rescue the brain phenotype
Building the infrastructure for patient-centered CER by identifying types of therapies to develop to treat SLC13A5 Epilepsy. ● *Which type of treatment is desired by patients?* ● *Are families willing to take daily/weekly/monthly or more invasive one-time treatments?*	
3. Model development and characterization	1. What are the relevant model systems that recapitulate human disease? 2. Can we characterize current model systems to determine which one(s) best recapitulate human disease? 3. What models can we test potential treatments? 4. Why is the point mutation mouse model more severely affected than the full knockout? 4. What are consistent and distinguishing phenotypes in each model?

Building the infrastructure for patient-centered CER by developing models that recapitulate different aspects of SLC13A5 Epilepsy. This will lay the groundwork to develop therapeutics to address different symptoms of disease that are important to families.	
4. Citrate in health and disease	1. What is the role of extracellular citrate in disease? 2. What is the role of citrate in epilepsy? 3. Is extracellular or intracellular citrate levels (or both) pathogenic? 4. At what point during development is citrate most important?
Building the infrastructure for patient-centered CER by: ● *Determining whether citrate may be an appropriate therapeutic target for SLC13A5 Epilepsy.*	
5. Mechanism	1. What are the downstream pathways affected by loss of function of SLC13A5? 2. What is the molecular disease mechanism? 3. What metabolic pathways are affected in SLC13A5 Epilepsy patients?
Building the infrastructure for patient-centered CER by: ● *By identifying additional therapeutic targets for SLC13A5 Epilepsy.*	
6. Affected cells and tissues	1. How does SLC13A5 impact different tissues and organs? (especially liver) 1. What is the role of SLC13A5 in neuronal subtypes? 1. What is the role of astrocytes in SLC13A5 Epilepsy? 2. What are all the affected cell types?
Building the infrastructure for patient-centered CER by: ● *Determining appropriate cells, tissues, and organs for therapeutic targets.*	
6. SLC13A5 variants	1. What is the genotype-phenotype correlation? 2. How are patient variants characterized? 3. How do patient samples behave in vitro?

Building the infrastructure for patient-centered CER by: ● *Providing a fundamental understanding of SLC13A5 variants. This will eventually help with diagnosis of SLC13A5 and help determine the most effective methods for diagnosing patients.*	
8. Translatability	1. How can we translate non-clinical model data into the clinic?
Building the infrastructure for patient-centered CER by: ● *Developing interventions and treatments in preclinical models based on what is most important to families*	
9. Epilepsy	1. What is the role of citrate in epilepsy? 2. What are the molecular and genetic mechanisms of epilepsy?
Building the infrastructure for patient-centered CER by: ● *Identifying the role of citrate in regards to one of the top patient-identified symptoms (seizures) will allow for relevant therapeutic development*	
10. Tool development	1. What methods are we missing to understand this disorder? 2. What tools do we need to develop to understand disease mechanism in the brain?
Building the infrastructure for patient-centered CER by: ● *Identifying relevant tools that we need to understand SLC13A5 Epilepsy and develop appropriate treatments*	

Infrastructure research priorities

The infrastructure section of our research agenda identifies important resources that will help the SLC13A5 community move towards patient-centered CER.

Table 4: Infrastructure research needs

Theme	Resources that would help advance SLC13A5 research
1. Funding/ grants	● More funding for SLC13A5 labs ● Establishing grant-writing communities ● Facilitating collaborative research proposals
2. Models	● Fully characterizing and publishing currently available models (rodent, zebrafish, patient-derived iPSCs) ● Establishing patient-specific *in-vivo* models
3. Stakeholder collaboration	● Creating opportunities to discuss results and increase collaborations ● Hosting patient and professional joint conferences to bring all partners together ● Increasing collaboration across all partners ● Improving integration across basic and clinical research
4. Researcher collaboration	● Building data sharing/databases for all SLC13A5 data: including negatives or failed protocols ● Curating human omics data analysis to learn from human data repositories ● Building an SLC13A5 research communication forum
5. Research resources	● Making SLC13A5 antibodies and nanobodies publicly available ● Registry of data, tools, and reagents for research community ● Availability of patient data ● Researchers using the available resources that have been developed (models and tools) ● Publicly available, centralized biorepository ● SLC13A5 structures in various conformations during citrate transport
6. Advocacy	● Public awareness campaigns

PARTNERSHIPS

There are many different partners who actively engage with the SLC13A5 Epilepsy community. This is a patient-centered community that supports active collaboration and communication amongst all partners.

Importantly, this research agenda was developed with input from our different partners. This community is also how we will distribute the research agenda in the future.

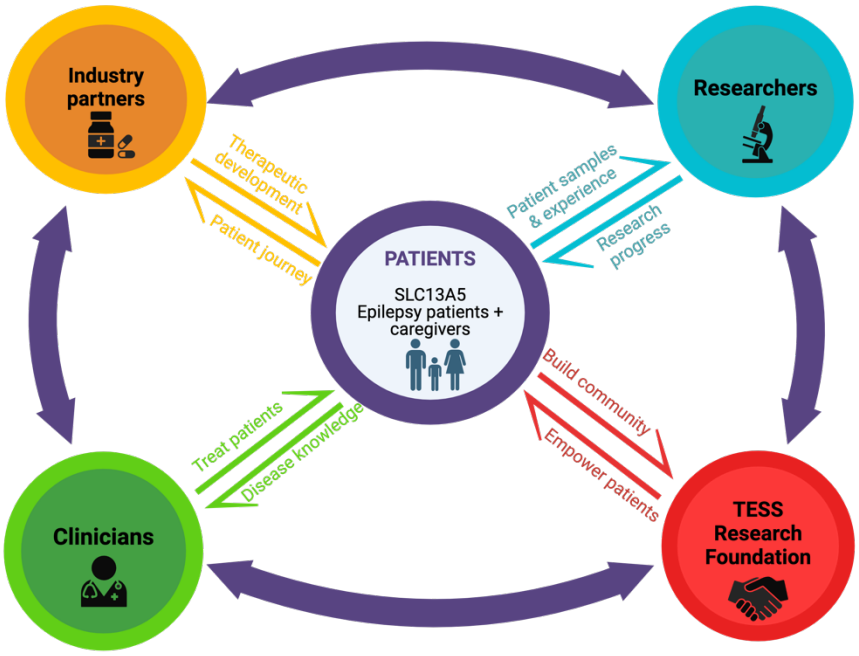

Figure 8 We are a community with many partners, each with a critical role to play.

TESS Research Foundation engages with the community on a regular basis. Table 5 identifies the TESS Research Foundation engagement lead and describes key strategies used to engage with each partner.

Table 5: Engaging with many partners in the SLC13A5 community.

	Patient	Research	Clinical	Industry
Engagement lead	TESS Family outreach coordinator and Executive Director	TESS Scientific Director	TESS Executive and Scientific Directors	TESS Scientific Director
Stakeholder engagement	• SLC13A5 Clinical Research Conference • Monthly family support group • Monthly e-newsletter • Quarterly print newsletter	• Individual communications • Peer-reviewed publications • Foundation website • Monthly e-newsletter • Research conferences (American Society for Gene and Cell Therapy, American Society for Neurochemistry) • TESS Scientific Advisory Board • SLC13A5 Research Community Updates (virtual seminar series)	• Patient identified clinicians • Clinical research conferences (American Epilepsy Society) • Natural History Study site PIs: Drs. Brenda Porter, Kim Goodspeed, Judy Liu	• Individual communications • Foundation website • Monthly e-newsletter • Research conferences (American Epilepsy Society, World Orphan Drug Congress)

How can each partner contribute and help us build capacity towards patient-centered CER?

Each partner has an important role to play as we build capacity towards patient-centered CER. One of the key themes of each of these action items is that we need to listen and learn from our patient community. This will help the SLC13A5 community build trusting relationships amongst all partners, develop the infrastructure to identify promising interventions, and move closer to patient-centered CER.

Some of the possible actions each partner can take to build capacity for patient-centered CER:

Figure 9 Potential activities partners can participate in to bring our community closer to patient-centered CER.

Patients:

- Participate in the SLC13A5 Epilepsy natural history study
- Join the TESS Research Foundation Registry
- Attend TESS Research Foundation family support calls (virtual)
- Increase awareness about SLC13A5 Epilepsy within your community

Researchers

- Listen and learn from affected families about top priorities and symptoms to address

- Collaborate with the research community
- Attend and present at the virtual monthly SLC13A5 Research Community Updates
- Address top research needs identified in our SLC13A5 research agenda
- Share your work: present your findings at conferences, publish your results, share with the patient community

Clinicians

- Listen and learn from affected families about top priorities and symptoms to address
- Connect with SLC13A5 Epilepsy experts and TESS Research Foundation
- Share your experience with clinical partners through conferences and publications
- Use our new ICD code to identify SLC13A5 Epilepsy patients: E74.820

Industry partners

- Listen and learn from affected families about top priorities and symptoms to address
- Include patients and families early in the therapeutic development process
- Share your findings: present your work at conferences and through publications
- Partner with TESS Research Foundation to learn about the demographics and needs of the SLC13A5 Epilepsy community

SUSTAINABILITY

We will continue to build towards patient-centered CER by continuing to engage regularly with our SLC13A5 community. TESS Research Foundation will host a patient-centered meeting in 2026 to bring our partners – patients, researchers, industry partners, clinicians, and others – together to answer the following questions:

1. How do we address the goals of our updated SLC13A5 research agenda?
2. How do we drive patient-centered CER for the SLC13A5 Epilepsy community?
3. How can we ensure patients are involved as active partners through all stages of the CER process?

In the spring of 2025, TESS Research Foundation received a PCORI Engagement Award to support this meeting: "Convening to advance SLC13A5 Epilepsy patient-centered CER." Here, we will continue to center the needs of the SLC13A5 Epilepsy community, discuss challenges and potential solutions to addressing topics in our updated research agenda, and identify working groups to that will meet regularly to identify promising strategies to address patient-centered CER. Although not a goal part of this award, TESS Research Foundation will continue to diversify our revenue stream to maintain our staff and ability to support these programs. We will also continue to collaborate with consortia and partners (COMBINEDBrain, Chan Zuckerberg Initiative Rare as One, Rare Epilepsy Network) and other rare disease groups to share resources. Overall, this will continue our momentum and progress towards patient-centered CER.

ACHIEVING OUR GOALS TOGETHER:

We will share our research agenda and roadmap with our SLC13A5 Epilepsy community through multiple mechanisms. We will record and share our research agenda and roadmap through a recorded webinar. We will share the recording with members so they can watch it asynchronously (video on demand). We will host the dissemination webinar on TESS Research Foundation's website, as well as share it through our stakeholder specific communications (Table 4). We will develop stakeholder specific communications regarding our research agenda, as well as our roadmap, and share these resources with families though our monthly family e-newsletter, quarterly print newsletter, family support group, and with our research community through the SLC13A5 Research Community Update meetings, as well as through our social media platforms. We will also host our research agenda and roadmap on our Foundation's website. Importantly, as we have a diverse and multi-lingual patient community, we will ensure our resources are accessible through multiple languages.

Sharing our research agenda will build the infrastructure to achieve our goals listed. These goals include addressing areas identified in our research agenda, as well as publishing the results. By sharing the research agenda with the broader community, this will share with all of our partners the needs of the SLC13A5 community. TESS Research Foundation will also review this roadmap annually to evaluate our progress towards our goals. This will be measured by ongoing collaborations, projects, and publications.

As a foundation, this research roadmap will determine which specific research projects we support both financially and otherwise. This includes putting TESS resources (personnel, financial, and volunteer resources) towards top priority projects. Additionally, we have incorporated sharing our research agenda and addressing top needs into our foundation strategic and operational plan to reflect the significance this living document plays to our organization. Overall, our community will use this research roadmap to continue driving patient-centered research at the translational and clinical levels, leading us to patient-centered CER.

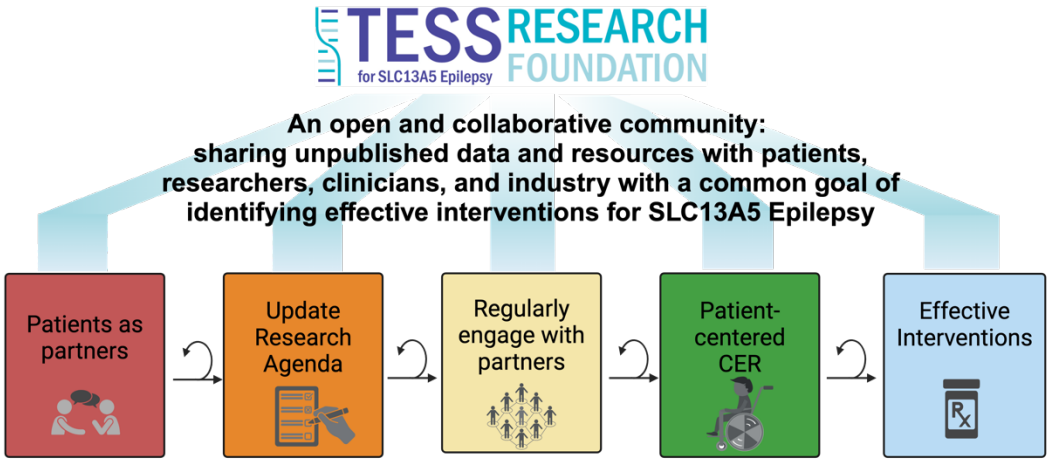

Figure 9 We will continue to work with patients as partners to update our research agenda, a living document. We will meet regularly with all partners and together, we will move closer to patient-centered CER to identify promising interventions for the SLC13A5 Epilepsy community.

We will continue to move forward with a sense of purpose, urgency, and community: helping those impacted by SLC13A5 Epilepsy.

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