

# Glut 1 Deficiency Foundation Strategic Plan

Created 4/8/2022

## Table of Contents

<b>Mission &amp; Vision</b>	<b>3</b>
<b>Strategic Planning Process</b>	<b>4</b>
<b>Plan Monitors</b>	<b>4</b>
<b>Schedule of Review</b>	<b>4</b>
<b>Participants</b>	<b>4</b>
<b>Messaging</b>	<b>5</b>
<i>What will we say?</i>	
<i>•We have strategically mapped out a plan to amplify our mission!</i>	
<i>Who will we tell?</i>	
<i>Where will we share?</i>	
<b>Environmental Assessment</b>	<b>6</b>
<b>Our Vision – “What if?”</b>	<b>8</b>
<b>The Barriers – “Why not?”</b>	<b>9</b>
<b>Strategic Directions – “Where to?”</b>	<b>9</b>
<b>Strategic Direction #1</b>	<b>10</b>
<b>Strategic Direction #2</b>	<b>11</b>
<b>Strategic Direction #3</b>	<b>12</b>
<b>First Year Accomplishments – “How to?”</b>	<b>13</b>
<b>First-Year Timeline</b>	<b>16</b>
<b>90-Day Implementation Plans</b>	<b>17</b>
<b>Appendices</b>	<b>21</b>

# Strategic Plan

July 1, 2022 – June 30, 2025

---

**Introduction** - The Glut1 Deficiency Foundation was formed originally in 2009 – born of a desire for families to get together to meet, share, and learn from one another. Glut1 Deficiency is such a rare diagnosis that many families, and especially our Glut1 children, never had the experience of meeting others who share this journey.

The Yahoo Health group was our original meeting place, and as our relationships evolved, we began talking about how good and helpful it would be if we could meet in person. Jen Lazar organized our first family meeting in Chicago, which quickly grew into a full-fledged conference when researchers and experts eagerly accepted our invitations to come join. The knowledge, experiences, and emotions shared at this first meeting impressed upon us the need to keep having these gatherings. As relationships developed with these experts, we soon learned that there were very few sets of eyes and very few dollars focused on researching Glut1 Deficiency – and we wanted to help change that.

A leadership group began to emerge, and we received our 501 (c)3 public charity designation from the IRS in July of 2011 with Lloyd Holleman, Jen Lazar, Keri Meyers, Glenna Steele, and Greg Stoddard as the founding board members. We have continued to grow our service programs and our impact, have expanded our Board of Directors, and have added both a Medical Advisory Board and Scientific Advisory Board to help guide our endeavors. In 2017, the G1DF appointed its first Executive Director, Glenna Steele, as an effort to meet growing needs and obligations more efficiently and effectively. In May of 2021, Sandra Ojeda was added as Science Director to oversee science and research activities.

The Glut1 Deficiency Foundation has a principal address in Evansville, Indiana and is incorporated in the state of Indiana. The operational headquarters are in Owingsville, Kentucky. While located in the United States, the G1DF serves an international patient community for the rare disease officially known as Glucose Transporter Type 1 Deficiency Syndrome.

Currently, there are eight board members, all parents of children with Glut1 Deficiency, and a staff of one full-time Executive Director, one part-time Science Director, one part-time Special Projects Director, and one part-time Science Advisor. Additionally, there are several volunteers who help with various special projects for the G1DF.

## Mission & Vision

**Vision:** We dream of a brighter future where Glut1 Deficiency will be easy to diagnose early, treat effectively, and cure completely.

**Mission:** The Glut1 Deficiency Foundation is a nonprofit patient advocacy organization dedicated to improving lives in the Glut1 Deficiency community through its mission of increased awareness, improved education, advocacy for patients and families, and support and funding for research.

## Strategic Planning Process

Through a series of focused conversations and consensus workshops, the participants:

- Conducted an **Environmental Assessment** – The group discussed basic information pertaining to the Glut1 Deficiency Foundation, and assessed the organization’s internal strengths, weaknesses, opportunities, threats, and achievements. The group then identified priorities to address during the strategic planning process;
- Created a **Practical Vision** for Glut1 Deficiency Foundation – The group developed a vision of what it wants to see in three years as a result of its strategic actions;
- Discussed the **Underlying Barriers** to achieving the vision – The group identified the blocks and barriers that may be preventing the organization from realizing its vision;
- Developed **Strategic Directions** for which the Glut1 Deficiency Foundation can aim – The group outlined broad, overarching themes that will help set the focus for change;
- Created a **Focused Implementation** plan – Finally, the group began to craft courses of action that will help to operationalize the strategic directions and move the Glut1 Deficiency Foundation toward its vision.

The group identified four general strategic directions with specific implementation steps outlined for each:

- 1. Equipping and Empowering the Glut1 Community**
  - a. Engage Glut1 Community
  - b. Increase Volunteerism
  - c. Provide Educational Resources
- 2. Improving Patient Outcomes**
  - a. Develop Collaborative Research Network
  - b. Improve Patient Quality of Life
- 3. Strengthening Organizational Engagement**
  - a. Expand Quality Human Resources
  - b. Strengthen Internal Operations
  - c. Maintain a Positive and Impactful Work Culture
  - d. Ensure Financial Sustainability

Although this strategic plan is intended to cover a three-year period, it is broken down into one-year increments, each containing specific accomplishments that, if addressed, will move the Glut1 Deficiency Foundation toward realizing its vision. It is intended that the detailed implementation plans developed for each accomplishment are reviewed/adjusted every 90 days to track progress and provide the opportunity for adjustments to the plans.

## Plan Monitors

1. Maria Rebbecchi, Board Member, Education Director
2. Glenna Steele, Executive Director
3. Jason Meyers, Board Member, President

## Schedule of Review

Every 90 days with a full review at the end of Year 1. Reviews will also occur during regular Board meetings.

## Strategic Planning Participants

- **Staff in attendance:** Glenna Steele, Executive Director; Sandra Ojeda, Science Director
- **Board members in attendance:** Jason Meyers, President; Rob Rapaport, Secretary; Debbie Stoddard, Treasurer; Erin Meisner, Advocacy Director; April Breen, Fundraising Director; Maria Rebbecchi; Education Director.
- **Other Participating members in attendance:** Thomas Rebbecchi, MD, Scientific Advisory Board Member; Keri Meyers, Founding and Former Board Member

## Messaging

### *What will we say?*

- We have strategically mapped out a plan to amplify our mission!
- We met, we shared, we learned about how to plan for the future and better serve our community!
- We've dug deep to analyze our work and to create a plan for growth and greater impact!

### *Who will we tell?*

- Patients and Families
- Donors
- Researchers and Clinicians
- Industry

### *Where will we share?*

- Feature on a blog post on our website about the strategic plan
- Reference it in newsletters
- Social media posts
- Other communications with the community and conference

# Environmental Assessment

*What are some of the facts and basic data that describe our current situation?*

## STRENGTHS

- ED demonstrates great leadership/work ethic
- Board has a sense of community - we care for each other and our kids
- We're well respected in the rare disease community by other non-profits and the scientific community
- We are open to new strategies to grow and to accomplish our mission; including awareness and newly diagnosed
- We have a very strong and integrated technical, medical, and scientific community
- We have a research plan (Research Compass) to guide our mission
- We have good tools including the website with extensive resources and social media pages
- Welcoming new families - packets, messages, community support system
- Well run family conference - glue for the community
- Dedicated, capable, compassionate leaders within the organization
- Sense of family - close-knit community
- The foundation has increased awareness and helped increase the number of patients diagnosed
- Glut1 is listed on more genetic testing panels which expedites diagnosis
- Consistent and reliable fundraising (peer to peer campaign/ love someone campaign)
- Networked with other rare disease organizations
- We have essential and committed experts for the community

## WEAKNESSES

- ED assumes extra work load and struggles to delegate
- ED is "irreplaceable"
- Lack of community engagement: volunteers (families or non Glut1 families)
- Lack of structured or formal volunteer training
- Low community participation in Community Connect Forum
- Volunteers have loved ones with complex medical needs/time consuming treatments
- We need more consistent funding sources for research-CZI grants are time limited.
- Currently have 10 consistent/core volunteers
- Understaffed
- We don't have a transition plan for new board members and officers
- Funding/engagement seems to be consistently the same families-need new family engagement
- Relying on Glut1 families to fundraise - stretched thin-need new fundraising strategies
- Staff is overextended resulting in "quantity and quality struggle"
- No dedicated/skilled staff for social media, resource development, volunteer management, technology, donor management
- Lack of diversity on the board (currently all parents of Glut1 patients)

## OPPORTUNITIES

- New grant opportunities for 2022
- Volunteer growth opportunities with willing people ready to work
- Fundraising/development opportunities to optimize giving/support
- Further develop scientific meetings - quarterly roundtables
- Pull in new researchers/grow the network
- Encourage and support more collaborations across scientific community
- Find a disease champion/celebrity
- Prevalence clarity - how many are really out there? Goals and strategies to find them!
- Community growth - numbers diagnosed and community engagement
- Enhance and complement what the Foundation is already doing
- Find more adults who have Glut1-having more resources and research on adults
- Regional Leaders in the US-for fundraising, family support, advocacy
- Opportunity to strengthen community support virtually

## THREATS

- We're a small organization and rare disease limits fundraising, research etc.
- Executive director has too heavy of workload
- Limited pool of people to step up and take on responsibilities-too much dependency on volunteers
- Too much on shoulders of families - rely on patient community for fundraising
- Uncontrollable situations such as changes in economic environment impact our fundraising
- Small pool of doctors/experts
- Legal threats - logo use, reputation
- Big pharma can be money driven-be careful and strategic in collaboration
- Lack of succession planning: ED, Dr specialists, board members
- Confidentiality of patient data as we progress towards NH study
- Decreasing availability of government and private money-hindering achievements over time-NIH and research funding are diminished or less accessible. Increased competition for grants.

## ACHIEVEMENTS

- Awarded a NEW \$150k grant from CZI (2022)
- Awarded and completed a \$450k CZI grant (2020)
- 1.5 staff positions (Executive Director 2017 and Scientific Director 2020)
- Scientific meeting - first one held in June 2021 was a huge success
- Grown our board size (currently 8 members)
- Good educational resources (website, brochures, videos, YouTube)
- Osmosis video resource-g geared towards families and medical community
- Successfully lobbied for an ICD10 code specific for Glut1 Deficiency (2020)
- Since inception in 2011, Glut1 DF has awarded \$1 Million in research funding
- Successful family conferences - 8 (in person) and 1 virtual
- Dedicated scientists doing a variety of science
- Good reputation/respect amongst families and experts
- Successful annual fundraiser - Love Some1 Campaign (consistent and/or increased \$ raised each year)
- Consensus Paper 2020-Experts/Doctors collaborated, discussed, agreed, and wrote a paper on topics such as symptoms/treatments/standards of care.
- Welcome packets, family network has been successful (139 in 2021)
- Zoom meeting and virtual community connections (started in 2020)
- Million Dollar Bike Ride Grant Funding Annually (In-person and virtual)
- International community engagement (Multiple countries have Glut1 support or advocacy groups-collaboration)
- Creation of Research Compass and new research engagement
- Started International Glut1 Day (2021)
- We have the designation of Platinum for Candid
- We are members of REN, NORD, and COMBINEDBrain
- We are growing our research tools like biorepository/cell line, brain bank led by Dr. Pascual

## Our Vision – “What If?”

*What do we want to see in place in the next 3 to 5 years as a result of our actions?*

### **Improved Quality of Life; Glut1 Patients/Families**

- Expanded and more robust research network
- A research framework understood by investigators
- Improved diagnostic testing
- Better treatments for Glut1
- Stronger medical and scientific advisory board
- An ongoing natural history study

### **Engaged Informed Community; Community**

- Increased volunteer involvement and family ownership
- Consistent engagement from the community
- Strategic partnerships expanded
- Clear, effective marketing and messaging strategy
- Clear (commitment) channels to community
- Regional leaders in the US
- More professional champions of Glut1
- Increased engagement in our online platforms

### **Effective Skilled Staff; Staff**

- Right staff for right job
- Ways to decrease Glenna’s overwork condition implemented
- Expanded staff capacity
- Competitive compensation

### **Dynamic Sustainable Capacity; Capacity**

- Consistent reliable funding plan implemented
- Increased fundraising capabilities
- Reliable succession planning in place
- Development professional secured
- Written partnership agreements in place
- Social media management plan created
- Standard operating procedures implemented
- Reporting and accountability process implemented
- Volunteer management process in place
- Increased donor retention

### **Proactive Responsible Board; Board**

- A board with concrete expectations
- Glut1 patient serving on the board or in an advisory role
- Non-Glut1 board member
- Right board members in right role
- Diverse board
- Focused use of board time and talents
- Job descriptions updated for board positions approved
- Annual board performance review being conducted



## The Barriers – “Why not?”

*What may be blocking us from moving toward our vision?*

### **Rare Disease Status Limits Opportunities and Resources;**

#### **Rare Disease**

- Not enough interest in Glut1 in medical field
- Glut1 is a rare disease
- Underdiagnosed due to lack of knowledge/experience of doctors
- Doctors not acknowledging adult diagnosis
- Limited number of researchers working on Glut1-DS
- No new treatment options
- Reduced funds for rare disease researchers
- Treatments are difficult and incomplete
- Limited pool of people to take responsibilities

### **Limited Mindsets Deters Growth;**

#### **Mindsets**

- Community perception that we don't need their help
- Our mindset of scarcity – especially having funding
- Community belief they aren't part of capability
- Negative prior experiences create mistrust
- Volunteers trouble committing

### **A Changing World Impacts Resources;**

#### **Resources**

- Economic conditions impact funding and resources
- Political climate impacts resources
- Discord among scientific community

### **Current Research Landscape Hinders Progress;**

#### **Competition**

- Researchers protecting their own agenda
- Competition among researchers often hinders progress and collaboration
- Researchers competing for a limited pool of money
- Intellectual property protection
- Researchers work in silos
- Data ownership

### **Complex Caregiver Demands Impedes Consistent Engagement;**

#### **Limited Time**

- Overwhelmed parents
- Board members stretched thin as caregivers
- Varying (time) capacity of volunteers and staff

## Strategic Directions – “Where to?”

*What innovative, substantial actions will deal with the underlying barriers and move us toward our vision?*

### Strategic Direction #1

#### Equipping and Empowering The Glut1 Community



- **Engage Glut1 Community**
  - Inspire families to engage
  - Provide childcare at meeting
  - Consistently host a meeting or survey community on their perception of our organization
  - Create regional community groups to enhance involvement
  - Explore ways to involve adult Glut1 patients
  - Create a welcoming and inclusive messaging strategy
- **Increase Volunteerism**
  - Generate a document with specific tasks for volunteers
  - Grow volunteer program
  - Create a page on the website with volunteer opportunities
  - Embrace volunteer efforts and make each feel appreciated
  - Create high-impact low-input volunteering opportunities
  - Offer one time or short-term volunteering opportunities
  - Communicate to parents on benefit of volunteering
- **Provide Educational Resources**
  - Create resources for parents regarding keto diet
  - Acknowledge economic impacts and provide resources
  - Teach truths about Glut1
  - Increase awareness about this disease across all stakeholders
  - Promote Glut1 and assist in early diagnosis

*Strategic Direction #2*

Improving Patient Outcomes



- **Develop Collaborative Research Network**
  - Engage and energize the adult neurology world
  - Bring researchers together for more collaboration and knowledge sharing
  - Continually improve research roundtable(s)
  - Develop an engaged increased collaborative research network
  - Reach out to researchers working in glucose metabolism
  - Promote research that is generalizable
  - Develop links with other organizations (Alzheimers, etc.)
  
- **Improve Patient Quality of Life**
  - Fund research in Glut1
  - Prioritize newborn screening tool
  - Fund research for better treatments and cures
  - Explore ways to offset food costs
  - Provide access to dietitian consultants

Strengthening Organizational Effectiveness



- **Expand Quality Human Resources**
  - Hire a support staff member for executive director
  - Recruit people with more time and experience
  - Fund and hire development position
  - Strategize a more diverse board to represent our community
  - Explore ways to engage Glut1 adults in decision-making
  
- **Strengthen Internal Operations**
  - Develop a staffing plan including succession
  - Create SOPs (standard operating procedures)
  - Streamline reporting and accountability processes
  - Define specific job descriptions for board members
  - Develop board performance criteria and measures
  - Survey NFPs (not for profits) for HR (human resource) issues (salary)
  - Develop clear expectations for board members
  - Address board term limits and how we will attain successors
  - Create contingency plans to weather the unexpected
  
- **Maintain a Positive and Impactful Work Culture**
  - Build a 'can do' mindset
  - Treat employees with respect
  - Create and model core values
  - Create an inclusive community
  - Hold ourselves to high standards
  
- **Ensure Financial Sustainability**
  - Keep a healthy surplus
  - Approach potential celebrity ambassadors to raise funds
  - Respond positively to current events
  - Develop a marketing plan to increase funding

## First Year Accomplishments – “How to?”

*What specific, measurable tasks will we accomplish in the first year?*

### Accomplishment List #1

## Equipping and Empowering the Glut1 Community

CURRENT REALITY	1 <sup>st</sup> YEAR ACCOMPLISHMENTS	2-3 YEAR SUCCESS INDICATORS
<ul style="list-style-type: none"> <li>● 850 individuals on the family mailing list (800 families)</li> <li>● 250 on professional mailing list</li> <li>● 5% engagement in annual fundraiser</li> <li>● We host 3 family fundraisers annually</li> <li>● 30 FB birthday fundraisers annually</li> <li>● 10 new volunteers as of April 2022</li> <li>● 1 parent assists with social media</li> <li>● Glut1 public FB page has 3500 followers</li> <li>● Some parents host private FB groups</li> <li>● New platform on discourse for family engagement (it's inactive and has 80 registered)</li> <li>● Pro./expert engagement platform in progress</li> <li>● 359 members in the family network</li> <li>● 79 professional network members</li> <li>● Host quarterly Zooms (20-25 parent participants)</li> <li>● Spanish Zoom meetings attract about 15 participants quarterly</li> <li>● Zoom mtgs for children (about 6 kids)</li> <li>● Zoom mtgs for adult patients (approx. 10 participants)</li> <li>● Hired a consultant to facilitate adult Zoom programs</li> <li>● Distribute Welcome Packets (139 in 2021)</li> <li>● Website is being updated currently</li> <li>● 330 unique visitors to website weekly</li> <li>● Have brochures to share with families and professionals</li> <li>● Invested in creating educational videos</li> <li>● Host bi-annual family conferences (9 to-date)</li> <li>● Have hosted 1 scientific conference</li> </ul>	<ul style="list-style-type: none"> <li>● Volunteer opportunities and onboarding processes finalized</li> <li>● At least one volunteer coordinator assigned to each of our programs</li> <li>● Discourse growth strategy established</li> <li>● Round Table growth strategy established</li> <li>● Community Engagement Assessment completed</li> <li>● Events calendar for 2023-2024 created</li> <li>● 1 regional pilot program planned</li> <li>● At least 3 new professional videos completed for website</li> <li>● Resource Assessment completed</li> <li>● New website launched</li> <li>●</li> </ul>	<ul style="list-style-type: none"> <li>● Volunteer management program operating efficiently</li> <li>● Discourse is recognized as Glut1's Community's go-to online platform for education/support</li> <li>● At least 300 Glut1 family participants registered on the Discourse platform (106 as of April 2022)</li> <li>● Increase Glut1 Community engagement on Discourse by 100%</li> <li>● Discourse for Professional will be explored if enough interest among researchers</li> <li>● Double the number of participants in our Research Round Tables (starting at 30 YTD which will be a goal of 60)</li> <li>● Increase the number of non-board members of volunteers (5 YTD) to 20 (300%)</li> <li>● Increase participation in our events (educational/support) by 100% (YTD 5%)</li> <li>● Expanded and updated resources</li> </ul>

Accomplishment #2

## Improving Patient Outcomes

CURRENT REALITY	1 <sup>st</sup> YEAR ACCOMPLISHMENTS	2-3 YEAR SUCCESS INDICATORS
<ul style="list-style-type: none"> <li>● Incidence rate is 1:24,000</li> <li>● Started research round table</li> <li>● Attend 6-8 various professional medical meetings annually</li> <li>● We have a part time science director</li> <li>● We fund research</li> <li>● We have awarded \$1M since inception to Glut 1 researchers</li> <li>● We collaborate with companies that have potential to develop newborn screening</li> <li>● We collaborate with medical food companies to provide support and resources to families</li> <li>● Consistent regular funding (at a minimum grant funding)</li> <li>● We are collaborative with pharmaceutical companies that have potential to develop treatments</li> <li>● Hosted our first virtual scientific conference in 2021 (230+ registered)</li> <li>● Host biannual family conferences (9 to-date)</li> <li>● Have list of dieticians on website</li> <li>● Refer to The Charlie Foundation to avoid duplication of Ketogenic diet information</li> <li>● Research compass created</li> <li>● Natural History study in development</li> </ul>	<ul style="list-style-type: none"> <li>● Full Time Science Director hired</li> <li>● At least one new exhibit opportunity secured</li> <li>● Proposal for Ketogenic Dietician Services presented to the board</li> <li>● Ethical clinical trial opportunities posted on our website</li> <li>● Actively engaging new adult neurologists</li> <li>● At least <u>4</u> new researchers engaging on our research compass</li> <li>● Natural History Study launched within patient community</li> <li>● Benefits assessment for Centers of Excellence completed</li> </ul>	<ul style="list-style-type: none"> <li>● Increase the reach of our educational exhibits for medical professionals by engaging at least 4 new medical societies</li> <li>● Professional Dedicated Ketogenic Dietician serving our Glut1 Community</li> <li>● Actively supporting biomarker development efforts</li> <li>● Actively sharing ethical clinical trial opportunities with our community</li> <li>● Double our network of adult neurologists (currently work with 5 YTD)</li> <li>● Double number of researchers collaborating on our research compass to 20 (10 YTD)</li> <li>● Natural History Study is ongoing and robust</li> <li>● Feasibility study for Centers of Excellence completed</li> </ul>

Accomplishment #3

## Strengthening Organizational Effectiveness

CURRENT REALITY	1 <sup>st</sup> YEAR ACCOMPLISHMENTS	2-3 YEAR SUCCESS INDICATORS
<ul style="list-style-type: none"> <li>● One FT employee and one half-time employee</li> <li>● No development position</li> <li>● Diverse board (ages of pt's, geography, spectrum of symptoms/treatments, pt experiences)</li> <li>● No SOPs/guidance documents</li> <li>● No staffing or succession plans</li> <li>● Current board term limits are 3 years times 3 times</li> <li>● Not using team mgmt. software</li> <li>● No expectation evaluation measures for leadership</li> <li>● No marketing plan</li> <li>● Have financial contingency plan</li> <li>● \$150K annual budget average (non grant years and not including research grants given)</li> <li>● 3 months operating reserve secured</li> <li>● Board works well together</li> <li>● Board is respected in the medical community</li> <li>● No core value statements</li> </ul>	<ul style="list-style-type: none"> <li>● Development position filled</li> <li>● Staffing analysis completed</li> <li>● Succession plan created</li> <li>● Job descriptions and expectations established for board and staff</li> <li>● Targeted marketing campaign approved</li> <li>● 1<sup>st</sup> annual development plan created</li> <li>● Job satisfaction evaluation tool created</li> <li>● Board restructured</li> <li>● Identified at least 2 new board prospects</li> </ul>	<ul style="list-style-type: none"> <li>● Organizational guidance documents current and relevant</li> <li>● At least 1 additional support staff hired</li> <li>● ED reports improved work/life balance</li> <li>● Increased financial support by 100%</li> <li>● Targeted marketing campaigns in place</li> <li>● At least a 3-month operating reserve maintained</li> <li>● Board and staff report high job satisfaction</li> <li>● Regular performance reviews (board and staff) being conducted</li> <li>● Board roster filled with qualified/active leaders</li> </ul>

## First-Year Timeline

What is our timeline for the First-Year (2020-2021) Accomplishments?

	Q 1 2022			Q 2 2022			Q 3 2023			Q 4 2023		
	JUL	AUG	SEP	OCT	NOV	DEC	JAN	FEB	MAR	APR	MAY	JUN
Equipping and Empowering the Glut1 Community	<ul style="list-style-type: none"> <li>Volunteer opportunities and onboarding processes finalized (*Glenna, Rob)</li> <li>New website launched (*Glenna, Sandra, Kelly)</li> </ul>			<ul style="list-style-type: none"> <li>At least 1 volunteer coordinator assigned to each of our programs (*Glenna, Rob, Board)</li> <li>Roundtable growth strategy established (*Sandra, Rob, Maria)</li> <li>Events calendar for 2023-2024 created (*Rob, Glenna)</li> <li>One regional level pilot program planned (*Erin, Maria)</li> <li>At least 3 new videos created for website (*Rob, Glenna)</li> </ul>			<ul style="list-style-type: none"> <li>Discourse growth strategy established (*Maria, Glenna)</li> <li>Resource assessment completed (*Maria, Erin)</li> </ul>			<ul style="list-style-type: none"> <li>Community Engagement Assessment Completed (*Glenna, April)</li> </ul>		
Improving Patient Outcomes	<ul style="list-style-type: none"> <li>Full Time Science Director Hired (*Glenna, Sandra, Board)</li> <li>Proposal for a Ketogenic dietician service presented to the board (*Glenna, Sandra)</li> <li>Actively engaging new adult neurologists (*Sandra, Maria, Erin, Tom)</li> <li>Natural History Study launched within the patient community (*Sandra, Glenna, Jason)</li> </ul>			<ul style="list-style-type: none"> <li>At least 1 new exhibit opportunity secured (*Glenna, Sandra)</li> </ul>			<ul style="list-style-type: none"> <li>At least 4 new researchers engaging on our Research Compass (*Sandra, Glenna, Rob)</li> </ul>			<ul style="list-style-type: none"> <li>Ethical clinical trial opportunities posted on our website (*Sandra, Rob, Glenna)</li> <li>Benefit assessment for Center of Excellence completed (*Sandra, Glenna, Erin)</li> </ul>		
Strengthening Organizational Effectiveness	<ul style="list-style-type: none"> <li>Targeted marketing campaign approved (*Glenna, Sandra)</li> </ul>			<ul style="list-style-type: none"> <li>Job descriptions and expectations established for board and staff (*Jason, Glenna, Board)</li> <li>First annual development plan created (*Glenna, Sandra, Board)</li> <li>Job satisfaction evaluation tool created (*April B., Jason, Debbie)</li> <li>Identify at least 2 new board prospects (*Jason, Board)</li> </ul>			<ul style="list-style-type: none"> <li>Resource Development position filled (*Glenna, Sandra, Board)</li> <li>Succession plan created (*Jason, Rob, Maria, Staff and Board support)</li> <li>Board restructured (*Jason, Maria)</li> </ul>			<ul style="list-style-type: none"> <li>Staffing analysis completed (*Glenna, Maria, Jason)</li> </ul>		

\*Indicate individuals who most likely participate in the implementation of the above accomplishments first name listed indicates the person who will spearhead the task, subsequent names indicate supporting team members. Review and edit assignments as needed.



## 90-Day Implementation Plans

What are implementation steps for the first-quarter accomplishments?

<b>STRATEGIC DIRECTION:</b> Equipping and Empowering the Glut1 Community		<b>ACCOMPLISHMENT TITLE (what):</b> New website launched		
<b>INTENT (why):</b> Engage, educate and inform Glut1 Community		<b>START DATE:</b> April 9, 2022		<b>END DATE:</b> June 30, 2022
<b>IMPLEMENTATION STEPS (how):</b>		<b>WHO:</b>	<b>BY WHEN:</b>	<b>WHERE:</b>
1. Content approval, additional pages		Glenna	April 20	Online
2. Review website draft		Glenna, Kelly	May 20	Online
3. Suggest revisions		Glenna, Kelly	May 30	Online
4. Approve final website		Glenna	June 15	Online
5. Launch website		Glenna	June 30	Online
<b>COORDINATOR:</b> Glenna <b>TEAM MEMBERS:</b> Board	<b>COLLABORATORS/PARTNERS:</b> Louder Agency	<b>EVALUATION MEASURES:</b> Approved website launched		<b>BUDGET:</b> \$8K
				<b>NEXT MEETING:</b> April 12

<b>STRATEGIC DIRECTION:</b> Equipping and Empowering the Glut1 Community		<b>ACCOMPLISHMENT TITLE (what):</b> Volunteer opportunities and onboarding		
<b>INTENT (why):</b> Engaged community and expand capacity		<b>START DATE:</b> April 9, 2022		<b>END DATE:</b> April 12, 2022
<b>IMPLEMENTATION STEPS (how):</b>		<b>WHO:</b>	<b>BY WHEN:</b>	<b>WHERE:</b>
1. Revised volunteer handbook		Glenna	April 9	Online
2. Host volunteer informational meeting		Glenna	April 9	Zoom
3. Review current procedures		Rob & Glenna	April 12	Zoom/online/email
4. Approve onboarding process		Rob & Glenna	April 12	Zoom/online
<b>COORDINATOR:</b> Glenna, Rob <b>TEAM MEMBERS:</b>	<b>COLLABORATORS/PARTNERS:</b>	<b>EVALUATION MEASURES:</b>		<b>BUDGET:</b> \$0
				<b>NEXT MEETING:</b>

<b>STRATEGIC DIRECTION:</b> Improving Patient Outcomes		<b>ACCOMPLISHMENT TITLE (what):</b> Actively Engage New Adult Neurologists		
<b>INTENT (why):</b> Broaden and expand adult medical community		<b>START DATE:</b> May 1, 2022		<b>END DATE:</b> Oct. 21, 2022
<b>IMPLEMENTATION STEPS (how):</b>		<b>WHO:</b>	<b>BY WHEN:</b>	<b>WHERE:</b>
1. Preliminary meeting to organize thoughts		Sandra, Maria, Tom	May 2, 2022	Zoom
2. Gather list of neurologists		Sandra, Maria, Tom	May 16, 2022	Zoom
3. Create (all of us) the email template to send to neuro		Sandra, Maria, Tom	May 30, 2022	Email/mti if needed
4. Email correspondence to Dr. Cervenka and staff		Sandra, Maria, Tom	May 30, 2022	0
5. Continue correspondence and organize at meeting		Sandra, Maria, Tom	July 13, 2022	In-person, San Diego
6. Send emails/invitations to participate in round table		Sandra, Maria, Tom	Sept 1, 2022	0
<b>COORDINATOR:</b> Sandra, Maria, Tom	<b>COLLABORATORS/PARTNERS:</b>	<b>EVALUATION MEASURES:</b>		<b>BUDGET:</b> \$0
<b>TEAM MEMBERS:</b>				<b>NEXT MEETING:</b> 10-21-2022

<b>STRATEGIC DIRECTION:</b> Improving Patient Outcomes		<b>ACCOMPLISHMENT TITLE (what):</b> Full-Time Science Director Hired		
<b>INTENT (why):</b>		<b>START DATE:</b>		<b>END DATE:</b>
<b>IMPLEMENTATION STEPS (how):</b>		<b>WHO:</b>	<b>BY WHEN:</b>	<b>WHERE:</b>
1. All action items completed, just pending board approval		Board		
2.				
3.				
4.				
<b>COORDINATOR:</b>	<b>COLLABORATORS/PARTNERS:</b>	<b>EVALUATION MEASURES:</b>		<b>BUDGET:</b> \$
<b>TEAM MEMBERS:</b>				<b>NEXT MEETING:</b>

<b>STRATEGIC DIRECTION:</b> Improving Patient Outcomes		<b>ACCOMPLISHMENT TITLE</b> ( <i>what</i> ): Natural History Study Launched within our Patient Community		
<b>INTENT</b> ( <i>why</i> ): Better understand lifelong patient experiences		<b>START DATE:</b> April 14		<b>END DATE:</b> July 13
<b>IMPLEMENTATION STEPS</b> ( <i>how</i> ):		<b>WHO:</b>	<b>BY WHEN:</b>	<b>WHERE:</b>
1. Finalize survey questions		Glenna and Sandra	April 14	Home
2. Finish symptoms and activities lists, glossary		Glenna and Sandra	April 22	Home
3. Meet with matrix to discuss final inputs		Glenna and Sandra	May 1	Zoom
4. Review portal mock-up		Glenna and Sandra	June 1	Online
5. Complete soft launch		Board	June 13	Board Meeting
6. Revisions if needed		Glenna and Sandra	June 30	Online
7. Launch and share with community		Glenna and Sandra	July 13	Conference
<b>COORDINATOR:</b> Jason	<b>COLLABORATORS/PARTNERS</b>	<b>EVALUATION MEASURES</b>		<b>BUDGET</b>
<b>TEAM MEMBERS:</b>		Launched survey		\$0
				<b>NEXT MEETING</b> May 1

<b>STRATEGIC DIRECTION:</b> Improving Patient Outcomes		<b>ACCOMPLISHMENT TITLE</b> ( <i>what</i> ): Proposal for a Ketogenic dietician service presented to the board		
<b>INTENT</b> ( <i>why</i> ): Improve ketogenic diet services and support for Glut1 Community		<b>START DATE:</b> April 15		<b>END DATE:</b> Sept 12
<b>IMPLEMENTATION STEPS</b> ( <i>how</i> ):		<b>WHO:</b>	<b>BY WHEN:</b>	<b>WHERE:</b>
1. Meet with Heidi Pfeiffer, RDN		Glenna	April 15	Zoom
2. Discuss info from Heidi		Glenna/Sandra	April 30	Zoom
3. Email medical food companies with idea		Glenna/Sandra	June 1	Email
4. Create proposal to pitch		Glenna/Sandra	May 30	Online
5. Discuss with medical food companies		Glenna/Sandra	July 13	Conference
6. Schedule Zoom follow-ups as needed		Glenna/Sandra	Aug 15	Online
7. Confirm partnerships		Glenna/Sandra	Sept 1	Online
8. Report proposal to board		Glenna/Sandra	Sept 12	Zoom
<b>COORDINATOR:</b> Glenna	<b>COLLABORATORS/PARTNERS</b>	<b>EVALUATION MEASURES</b>		<b>BUDGET</b>
	Heidi Pfeiffer or other dietician, medical food companies, KetoVie, Vitaflo, Nutricia, Medica Nutrition, Functional Formularies	Proposal Complete		\$Salary/time
				<b>NEXT MEETING</b> April 15

<b>STRATEGIC DIRECTION:</b> Strengthening Organizational Effectiveness		<b>ACCOMPLISHMENT TITLE</b> ( <i>what</i> ): Targeted marketing campaign approved		
<b>INTENT</b> ( <i>why</i> ): Increase engagement		<b>START DATE:</b> April 30		<b>END DATE:</b> May 30
<b>IMPLEMENTATION STEPS</b> ( <i>how</i> ):		<b>WHO:</b>	<b>BY WHEN:</b>	<b>WHERE:</b>
1. Complete planning conversations with Louder Agency		Glenna	April 30	Zoom
2. Secured proposed plan from Louder Agency and share with board via email		Glenna	April 30	Email
3. Present plan to the board and solicit feedback		Glenna and Board	May 9	Board Meeting
4. Incorporate feedback		Glenna	May 23	Online
5. Finalize and approve the plan with Louder Agency		Glenna	May 30	Online
<b>COORDINATOR:</b> Glenna	<b>COLLABORATORS/PARTNERS</b>	<b>EVALUATION MEASURES</b>		<b>BUDGET</b>
<b>TEAM MEMBERS:</b> Board	Louder Agency	Approved plan in-hand		\$2500 Paid
				<b>NEXT MEETING</b>
				April 30

# Appendices