



## **Stroke Leadership Council**

### **Quick recap**

The team discussed Bonita's recent medical experience and reviewed ongoing projects including presentations, website updates, and social media engagement strategies. They explored challenges faced by stroke survivors after hospital discharge, particularly regarding access to necessary medical care and rehabilitation services, and discussed the importance of including rehabilitation in the overall stroke care system. The group planned upcoming presentations and events, including language sessions and adaptive sports discussions, while also addressing the need for enhanced support for teen stroke survivors and their caregivers.

### **Next steps**

- Kimia to prepare and conduct an introductory session on language plasticity before September 23rd
- Kimia to organize a Q&A session with Layli about stroke survivor experiences
- Kimia to develop guidelines for teen stroke group Discord channel discussions
- Kimia to explore funding opportunities for community reintegration programs
- Susan to ask Sarah to provide Layli with a PDF version of the headhunter presentation
- Preeti to review and select potential speakers from the provided spreadsheet
- Preeti to arrange for a physiatrist to speak about adaptive sports for stroke survivors
- Team to meet again on Tuesday, October 7th at 9 PM Eastern time
- Preeti to reach out to Dr. Christina Graeley and Dr. Katrina Marie Nayak to see if they would give a talk
- Preeti to introduce potential speakers to Susan for a 15-20 min presentation
- Preeti to organize speakers to talk about adaptive sports and its benefits
- Preeti to arrange a speaker to discuss job opportunities for stroke survivors



- Preeti to find a speaker to talk about new technologies and gadgets in rehabilitation
- Preeti to arrange a psychologist to discuss behavioral health issues
- Kimia to update the list of questions from stroke survivors and include recent meetings
- Preeti to suggest resident speakers for presentations if faculty members cannot participate
- Preeti to set up a date for physiatry presentation
- Susan to prepare a list of questions for potential speakers
- Preeti to consider adding flyers on the website for research studies looking for volunteers

## **Summary**

### **Team Updates and Meeting Frequency**

The group discussed Bonita's recent medical experience, including her knee replacement surgery and subsequent stroke treatment involving tourniquets and TPA medication. Susan and Layli had a brief conversation about their schedules and connecting offline. The meeting then began with Susan introducing the agenda, which included updates on current work, future planning, and action items, with a suggestion to potentially adjust the meeting frequency from every 6 weeks. Kimia joined the call briefly before the meeting officially started.

### **Project Updates and Future Planning**

The team discussed ongoing projects and upcoming tasks. Layli confirmed she had worked on one headhunter presentation and was ready to work on three more before year-end, pending Susan's approval to share the final version. Kimia reported progress on building a brand kit with Nagar and noted increased engagement on Slack, with plans to cross-promote social media posts and



encourage member donations. Kimia also mentioned moving to Chicago and outlined plans to approach partner organizations for funding, particularly for the caregiving section.

## **Language Plasticity Presentation Series**

Kimia plans to give two presentations on language and brain plasticity, with the first being an introductory session on September 2nd and the second, a more detailed presentation on September 23rd. Preeti offered to join the second session and suggested bringing in a neurologist to speak about language plasticity after strokes. Susan agreed to provide an overview of the September 2nd session to help prepare for the more technical presentation on the 23rd.

## **Stroke Support Group Planning Meeting**

The team discussed plans for upcoming presentations, with Kimia planning to cover aphasia, apraxia, and dysarthria, and potentially including a Q&A session with Layli sharing her survivor experience. They reviewed the updated website, which Kimia noted now contains comprehensive information, and discussed strategies for advertising the organization. Susan shared updates about the young stroke and teen stroke support groups, noting challenges with caregiver support and the need for a new grant writer as their current one is no longer interested in the project.

## **Enhancing Post-Hospital Stroke Care**

The group discussed the challenges faced by stroke and brain injury survivors after hospital discharge, particularly the lack of access to necessary medical care and rehabilitation services. Susan highlighted the need for continuity of care, including follow-up appointments with neurologists and access to physiatrists (rehabilitation doctors) who can address the whole body's function. Preeti, a physiatrist, explained their role in rehabilitation, focusing on recovery



and substitution strategies using technology. The group agreed that more awareness and access to physiatrists are needed, with Preeti offering to create a presentation about physiatrists' role in rehabilitation.

## **Rehabilitation Focus in Stroke Care**

The group discussed the importance of including rehabilitation in the overall stroke care system, noting that it was previously overlooked. They agreed to focus on community reintegration as a key aspect of their work, with plans to seek funding for this initiative. The team also discussed supporting teen stroke survivors and their caregivers, with Susan suggesting the need for enhanced support for both groups. Kimia highlighted the challenges faced by parents of teen stroke survivors and the potential for using Discord and other platforms to facilitate communication and support.

## **Story Sharing and Next Steps**

The group discussed Susan's experience with a stroke at age 9 and her challenges returning to school, which Preeti suggested could be an inspiring story to share with the children they're helping. They agreed to meet again on Tuesday, October 7th at 9 PM Eastern time, with Kimia planning to coordinate with Layli beforehand. The meeting will follow their language presentations, and Susan will remember to clarify the time zone for participants.

## **Headache, Stroke, and Adaptive Sports**

Preeti discussed the importance of headache physicians, particularly neurologists who specialize in migraines and their link to strokes. She suggested reaching out to doctors like Christina Graeley and Katrina Marie Nayak for potential talks, emphasizing the need for them to communicate in non-medical language. Susan shared her experience with adaptive sports and mentioned a previous project involving a grant for the NIH. Preeti introduced the idea of



inviting Dr. Cordova from Johns Hopkins to discuss the benefits of adaptive sports for community reintegration, focusing on opportunities for individuals to engage in activities like surfing, skiing, or sailing.

## **Stroke Recovery and Rehabilitation Initiatives**

The group discussed several topics related to stroke recovery and rehabilitation. Susan highlighted the need to explore job opportunities for stroke survivors, particularly in their home environments, and mentioned the importance of updating survivors on new rehabilitation technologies and treatments. Preeti offered to arrange expert speakers on various topics, including technology for walking, hand function, and behavioral health, and Kimia suggested creating a Q&A format for common questions about stroke. The group also discussed the lack of coverage on medication management, alternative therapies, and mental health support, with Preeti agreeing to find a neurologist to speak on medication policies and alternatives.

## **Speaker Planning and Presentation Guidelines**

Preeti will contact potential speakers to arrange 15-minute presentations at 7:30 PM Eastern, with a 7:35 PM start time, followed by 10-15 minutes for questions. Susan suggested having residents present on physiatry/rehab topics on October 17 if no other speakers are available, as this would benefit their resumes. The group discussed clinical trials research presentations, agreeing that speakers should give a general overview for 25-35 minutes before discussing specific location details in the final 10 minutes, to accommodate participants from different areas. Susan also mentioned she would be holding a board of directors meeting in the next 2-3 weeks.