

Academia-biotechnology-advocacy partnership: a case study of multi-stakeholder engagement in development of an omnichannel patient/caregiver tool

John Norwood,^a Patricia Penovich,^b Tracy Glauser,^c Lucretia Long,^d Cyndi Guerra,^e Adrian L. Rabinowicz,^e Enrique Carrazana,^{ef} Laura J. Herold^a

WHAT WAS THE OBJECTIVE?



We hypothesized that initiatives developed collaboratively by stakeholders from academia, the biotechnology industry, and patient advocacy groups could have a broad impact on patient care

WHAT DOES THIS CASE STUDY SHOW?



The case study presented here describes an initiative to overcome barriers to the adoption of acute treatment action plans, including the appropriate use of antiseizure medications that can be used when indicated

HOW WAS THE INITIATIVE DEVELOPED COLLABORATIVELY?

WHAT WAS THE PROCESS AFTER THE MEETING?

How was the group of stakeholders assembled?



A **scientific council** was initiated with financial support from Neurelis Medical Affairs and organized by independent academic co-chairs along with the sponsor's experienced clinical specialists



The co-chairs and prospective members were invited to take part in the **Neuroscience Council** based on their epilepsy expertise and standing in the medical and advocacy communities

How was the meeting conducted?

An inaugural closed-door meeting was convened in February 2020 to develop strategies and recommendations based on expert opinion agreement for overcoming the underutilization of available treatment action plans



Underuse of such plans is associated with worse outcomes and inappropriate healthcare utilization^{1,2}



At the meeting, the Neuroscience Council **identified the limitations of current action plans** and then proposed, discussed, and agreed on a set of principles for **developing concise, individualized treatment action plans that would be easy to use in acute situations** by caregivers with limited experience

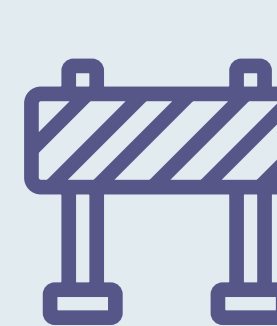


Guidance included using practical illustrations and symbols, checkboxes, and color coding illustrating a hierarchy of severity and appropriate treatment

The publication is freely available from *Epilepsy & Behavior*




After the meeting, **Council members developed a manuscript²** describing their agreed-upon expert opinion recommendations for treatment action plan development, use, content, and format; medical writing and logistical support was provided by The Curry Rockefeller Group, a Citrus Health Group company, which was supported by Neurelis, Inc.



The authors found a **lack of unified guidance** in the literature and **limitations to current plan formats** for customizability and practical use

The authors developed the **Acute Seizure Action Plan (ASAP)** as an example to illustrate the Council's guidance and included it in the manuscript



The publication has **30 Google Scholar citations** and an **attention score in the top 10% of research outputs** tracked by Altmetric

The sample plan has been adopted by advocacy organizations with downloadable translations,³ with additional advocacy organization adoption underway

Epilepsy Alliance America | Seizure Action Plan Coalition



WHAT ARE THE KEY TAKEAWAYS?

The ASAP tool was designed to overcome barriers to appropriate acute seizure care, as well as to provide a tool to support patient and caregiver education

- The template plan has been adopted by members of the epilepsy community

A multi-stakeholder partnership can offer important initiatives that put patients' and caregivers' medical and emotional needs first

- Such a collaboration can support the interests of all stakeholders in promoting a common goal, such as reducing healthcare system utilization and supporting appropriate medication use
- Medical/scientific communications professionals are in an ideal position to translate discussions into concrete publications and tools

This type of partnership has the potential to improve patient care meaningfully and can be implemented in a wide variety of disease states

References

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How was the partnership organized?



Support
Biotechnology Medical Affairs



Inaugural Council Meeting:

- Academic Co-Chairs
- Medical Experts
- Advocacy Representatives
- Pharmacologists
- Advanced Practice Providers
- Biotechnology Medical Experts
- Meeting supported by Agency's Medical Communications Professionals



Development of Manuscript With Example Treatment Action Plan

- Academic Co-Chairs
- Members of the Council
- Facilitated by Medical Writer and Agency



Evaluation of Plan in Real-World Practice



Integration of Plan Into Electronic Medical Records Platforms



Essentials for Creation

- Simple** to understand and personalize
- Easy-to-use**, with helpful, stepwise guidance



Putting the Plan Into Practice

- Uniform** action plan design and interpretation
- Use as an **educational** resource
- Save copies where they will be **readily available** (eg, consistent location in electronic medical records)
- Keep up to date** to reflect changes in treatment or condition and review periodically



More recently, a study **evaluating the use of the ASAP in an adult outpatient clinical setting** found a **significant increase** in patient and care-partner knowledge and comfort scores for emergencies following plan implementation, and **98% of participants felt that all patients should have such a plan⁵**



An initiative to **integrate the plan into a major electronic medical records system** is in development

Disclosures

JN and LJH are employees of The Curry Rockefeller Group, a Citrus Health Group company. PP, TG, and LL are consultants to Neurelis, Inc. CG and ALR are employees of and have received stock options from Neurelis, Inc. EC is an employee of and has received stock and stock options from Neurelis, Inc.