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Review

Recommendations for development of acute seizure action plans (ASAPs) from an expert panel



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ABSTRACT

Purpose of review: Disease-related treatment action plans for acute exacerbations providing information that may be helpful for self-management for patients and caregivers are commonly used for chronic conditions such as asthma and diabetes. However, among patients with epilepsy, a review of the literature suggested that the majority did not have an action plan in place for acute seizure treatment.

Recent findings: Currently, there is a lack of unified guidance on seizure action plans (SAPs) in the literature. In the authors' opinion, available formats have limitations for practical use and may not be easily customizable to individual patients, and they are not often designed to provide simple-to-follow steps for rapid immediate steps to determine and initiate appropriate treatment of seizure emergencies. Our group reviewed current examples of SAPs and provided guidance on the development of acute seizure action plans (ASAPs) designed to facilitate rapid, appropriate acute care in the community and to be as useful as possible for a wide range of care partners, including those with limited experience.

Summary: This paper provides agreed upon expert opinion recommendations and considerations for goals, development process, types of content, and format for an ASAP.

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1. Introduction

Treatment action plans providing instruction on appropriate acute-treatment management can be used by healthcare providers (HCPs) to engage patients and caregivers to actively participate in their own healthcare [1,2]. Action plans can supplement education from HCPs and can be customized to individual patients [1]. These types of plans have been successfully developed for chronic conditions such as asthma and diabetes [3,4].

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Seizure action plans (SAPs) are broadly based descriptive and daily treatment summaries for patients with epilepsy, but the majority of patients do not personally have them [5]. In a Harris poll that included 259 adult patients with epilepsy experiencing seizure clusters (intermittent, stereotypic episodes of frequent seizure activity) in the past year, only 30% responded that they had a seizure emergency plan in place [5]. Pediatric patients with epilepsy are more likely to have an SAP in place than adults; in one study of survey results from 100 families, 45% of pediatric patients had SAPs [6]. A clearly understood plan with information on what to expect and do during an acute seizure episode may help curtail the burden of epilepsy [5].

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Abbreviations: ASAP, acute seizure action plan; ED, emergency department; HCP, healthcare professional; SAP, seizure action plan; SUDEP, sudden unexpected death in epilepsy.

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2. Why acute SAPs (ASAPs) are needed for persons with epilepsy

As background to development of their recommendations based on expert opinion agreement, our group discussed why ASAPs. which have a focus on immediate identification and applicable treatment of seizure emergencies, are needed specifically for patients with epilepsy, including incidence, costs, and epilepsyspecific anxiety. A broad range of literature was surveyed by the authors in which numerous terms were used to describe plans for use of rescue medicines. As proposed in the recent Epilepsy Foundation consensus paper, the term "seizure action plan" was used as the preferred term [2], with "acute seizure action plan" used for plans providing details for acute treatment and designed to be used at the time of a seizure or recurrent seizure. This paper provides a framework for development of an ASAP that is intended for customization as appropriate per personal, cultural, legal, and regulatory contexts. Recommendations presented here should be applied at the HCP's discretion per the needs of his/her individual patient. ASAPs are educational tools, and one set of recommendations may not meet the educational needs of everyone.

Acute seizure episodes, such as seizure clusters, can occur spontaneously and unpredictably [7]. Patients and caregivers may not feel adequately prepared to control these episodes. Anxiety surrounding these seizures can lead to increased patient issues, such as concerns about lack of independence and inability to work or participate in daily activities (Table 1) [5]. Notably, many of these concerns may be addressed by an ASAP.

According to the Centers for Disease Control and Prevention, approximately 3.5 million Americans have epilepsy (3 million adults aged \geq 18 years; 470,000 children and teens), and 56% of adults taking medication for epilepsy still have seizures [8]. The average annual total direct costs alone for a person with epilepsy range from approximately \$10,000 to \$48,000 (2013 dollars) [8]. A systematic review that included 22 studies with economic outcomes found a substantial economic burden for individuals with epilepsy, their families, and healthcare systems, due to direct and indirect costs [9]. Medications and hospital services were major direct costs; indirect costs included productivity loss, such as lower income and unemployment [9]. Of note, a study in patients with seizure clusters found that rescue medication use was inversely associated with hospital visits [10]. The investigators conducted an analysis in 26 patients who used rescue medication at least once in a year and compared seizure events in which rescue medication was and was not used. Use of rescue medication was significantly associated with fewer injuries (2.1% vs 91.5%; P < 0.0001) and emergency room visits (5.2% vs 16.9%; *P* = 0.0239) [10].

Table 1

Patient- and caregiver-reported areas in which seizure clusters have a negative impact on patients' lives [5].

Seizure clusters negatively impact the following:	Patients, % (n = 259)	Caregivers, % (<i>n</i> = 263)
Ability to drive	69	80
Job/career or ability to work	69	70
Overall mood	69	72
Ability to be independent	67	72
Ability to travel	59	54
Ability to participate in extracurricular activities	58	66
Ability to participate in hobbies and social activities	57	57
Relationship with friends and family	47	40
Ability to perform activities of daily life	46	44
Ability to help others in need	41	35
Ability to take a vacation	46	46
Sex life	35	40
Other	33	26
Ability to care for my/their children	23	31

Use of an ASAP can reinforce appropriate and timely care in seizure emergencies, such as the use of rescue medication, and offer increased control and decreased vulnerability to patients and caregivers by providing consistent guidance regarding epilepsy management that is specific to patients regardless of setting. Use of an ASAP may provide clarification on patient and caregiver concerns, such as understanding what to do during a seizure, when watchful waiting is appropriate, when to call 911 or go to the hospital, geographic issues, and age-related differences in treatment [11,12].

Promoting understanding and defining use of rescue therapy with an ASAP may reduce potentially unnecessary emergency healthcare utilization and will decrease direct and indirect costs. In rural areas, patients and caregivers may have to travel to distant healthcare facilities. The ASAP can be particularly helpful in guiding home management of seizures [13], which may in turn prevent sudden unexpected death in epilepsy (SUDEP) and reduce visits to the emergency department (ED). In a randomized controlled trial of one SAP, although healthcare utilization was not affected, caregivers for patients with epilepsy receiving an SAP were more comfortable with seizure care and missed fewer appointments [14].

3. Recommendations for ASAP development and use

3.1. ASAP development

3.1.1. In the medical practice

Development of an ASAP should involve cooperation among the patient, caregiver, and HCPs to create a customized plan tailored to the patient [15]. The physician (e.g., epileptologist, general practitioner, neurologist, and pediatrician), advanced practice provider, or other office practitioners along with the patient and caregiver should develop the ASAP based on the patient's history, seizure type, and seizure profile. During the development process, office visits should include discussion of goals for the ASAP and strategy for meeting them [16]. There may be differences between patients with new-onset epilepsy and those with continuing epilepsy that will shape the goals of the plan (e.g., to allay new patient fears and to provide a clear management strategy for continuing patients). Legal and regulatory issues related to sharing medical information with outside persons, agencies, and institutions also should be discussed during these visits.

For HCPs, development of the ASAP is an opportunity to educate the patient and caregiver regarding the patient's specific seizure type(s) and which situations (e.g., onset of aura, seizure cluster, and prolonged seizure/status epilepticus) call for emergency action [17,18]. ASAPs can be useful for educating a broad base of patients and their caregivers about the seizure medications and the status of their epilepsy, as well as for delineating patient-centered goals and strategies for achieving them. The terminology and information provided should then be consistent for all involved and is uniformly presented to all involved with the individual patient.

Once the structure of the plan is in place, the development team should work together to monitor how the plan actually performs when used, so potential revisions can be made as needed [16]. Thus, the format of the ASAP should allow for modification at future office visits based on patient and caregiver perceptions of ease of use, usefulness, helpfulness for reducing burden, and likability of the platform [16] or if a treatment change occurs. The ASAP should be reviewed by the patient and physician or provider regularly to ensure that it is understood and to determine whether it needs to be updated.

3.1.2. In emergency departments

Seizures, whether due to epilepsy or other causes, have been reported to account for 1% of ED visits (\sim 1 million annually) in

the United States, with high proportions of these visits among infants and toddlers, males, African-Americans [19,20], and persons with epilepsy. A quality improvement project including development and implementation of an ASAP for high utilizers of the ED was shown to improve knowledge of home seizure management and to decrease unplanned ED visits in some cases [21]. Similarly, an ASAP developed during a hospital visit can provide details on medications and instructions for use, instructions for treating seizures, and a follow-up plan for the patient at discharge [22]. Additionally, in conjunction with medical practices, a generalized version of an interim ASAP could be available from the hospital ED that would guide patients from ED discharge until the next visit with their HCP, thus avoiding possible need for transport if another seizure or cluster should occur.

3.1.3. Using Telehealth

Telehealth involves providing medical information and services using phone calls, texting, video conferencing, and/or mobile applications [23–25]. Telehealth may be useful to facilitate development of an ASAP or revision of an ASAP when geographic remoteness, transportation, travel costs, or patient illness (e.g., infectious disease) precludes office visits [26]. Many electronic health records or third-party platforms (e.g., seizure tracker) allow visualization of the ASAP within the patient portal. New tools, such as wearable technology, which currently includes smart watches with relevant applications and special watches for monitoring seizures [27], as well as audio or video monitors that notify a caregiver that a patient is having a seizure and may need assistance, may be needed to assist patients and caregivers in selfmonitoring and assessing risk of emergency situations, such as SUDEP [28]. They can then promptly initiate the ASAP.

3.2. Primary users of the ASAP

3.2.1. Patients and caregivers

All adult and pediatric persons with epilepsy could benefit from a plan for their self-management, especially those with new-onset epilepsy and those with ongoing frequent convulsive seizures who had >1 seizure in the previous year. An ASAP may contribute to the management toolkit. Seizure-free patients who have risk factors for breakthrough seizures may also benefit from an ASAP [29]. Key patient and caregiver subgroups for whom the ASAP may be particularly useful are listed in Table 2.

3.3. Secondary users of the ASAP

In addition to the primary users above, there are potential secondary users of the ASAP, such as school staff, coworkers, babysitters, and medical personnel including emergency medical technicians.

3.3.1. In schools

Seizure events in children are common in schools, so school personnel will need access to the child's ASAP. The school nurse and staff should be aware of a student's epilepsy, know when to initiate treatment, know when it is or is not appropriate to send a student home, and know when emergency assistance may be appropriate [30]. Onsite school nurses and other school staff are in a key position to support students with epilepsy [18]. They can manage seizures, create a safe recovery place, and provide postictal care [31]. They need to be empowered to provide appropriate seizure care based on the student's medically authorized plan [32]. General information from the ASAP can be used to educate student populations about epilepsy. In the United States, the Epilepsy Foundation has endorsed adoption of a general Seizure Action Plan in their Seizure Smart School curriculum. This initiative

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Table 2

Key subgroups of patients and caregivers for whom an acute seizure action plan will be particularly useful.

Patients who

- Need help to identify their normal seizure pattern, when a situation is an emergency, and how to respond [30,44]
- Have intractable epilepsy syndromes (i.e., Lennox-Gastaut, Dravet)
- Have frequent nocturnal generalized tonic-clonic seizures or generalized seizure and greater risk of sudden unexpected death in epilepsy with nocturnal convulsions
- Require support for maintaining dignity and independence [30] and alleviating fear of having a seizure at any time [5]
- Require guidance for prevention of an injury [45]
- Are in a group that may have special concerns (e.g., young children, older adults, patients with developmental disabilities) [12]
- Are at high risk for seizure clusters [48]
- Live far from medical care or in assisted living [37]
- Use virtual healthcare
- Are adults who do not have a plan in place

Caregivers who

- Are new to epilepsy or new to caring for persons with epilepsy
- Need to boost their confidence in their competency to control seizures and reduce anxiety/stress over unpredictability of seizures [14,44]
- Need help determining what is and is not an emergency
- Have needs/concerns about the patient's seizure profile and treatment (e.g., unclear on what the medication is, when to use it, and/or what to do if seizures continue after administration) [39], as well as their own burden related to epilepsy (e.g., effect on the ability to work, travel, and take part in social activities) [5]
- Need empowerment to address mental health issues (e.g., depression) associated with caregiving [49]

has led to a number of states passing legislation implementing training, recognition, and appropriate response to students experiencing seizures in public schools [33,34]. The Epilepsy Foundation of Australia has undertaken similar efforts in developing the Epilepsy Smart Schools program to promote a safe and inclusive environment for students with epilepsy [35].

Other school staff may require access to the ASAP to be able to know the child's health history, administer first aid, identify emergency and nonemergent conditions, administer emergency medication, and know what to do if rescue medication is ineffective [18,30,31]. One survey of 83 school nurses found that although virtually all (97.6%) were confident of their ability to identify a seizure, nearly half (43.4%) felt they lacked information on the nature and management of seizures in specific children [36]. The plan should be adaptable and clear for laypersons, especially in cases where there is no onsite nurse [36,37]. For quick use, the plan could include a separate customizable page to call a parent or guardian and to obtain permission to use the ASAP. Using one standard ASAP from a medical provider that is accepted by schools could assist in curtailing the current variability when schools require their own specific forms. Schools should be encouraged to accept the ASAP from the qualified HCP.

3.3.2. In the workplace

The negative impact of seizure clusters on a patient's job or career may include possible discrimination and embarrassment, lost work time, missing a work deadline, issues with driving, and job termination [5,29]. Coworkers may be uncomfortable observing a seizure or providing first aid [18]. Education gained through extensive experience with other conditions for which acute-treatment plans have been used may be helpful [14,16,21,38]. The ASAP can help with providing a patient-specific effective response to a seizure occurring in the workplace [17]. For example, the ASAP can be used to make coworkers aware of the patient's epilepsy, provide a description, direct seizure first aid, and specify if and when emergency medical services should be called.

3.3.3. In the home

Babysitters, grandparents, and other infrequent caregivers will benefit from an ASAP's guidance if a seizure occurs when the patient is in their care. The ASAP needs to be clear and useful enough for someone to implement if he or she does not have special knowledge of epilepsy.

3.3.4. In medical facilities

For the ED, the ASAP should be readily accessible and concise for use in emergencies, particularly when the individual patient is not well known to medical personnel. The ED would then have accurate information about the treatment and medications already received by the patient before the arrival to the ED. Having a documented ASAP in electronic medical records should be a quality measure for epilepsy care that is used with an eye to both incentives and consequences. The ASAP also may be helpful when the patient is in an outpatient clinic or hospital, to educate medical personnel about how to control that particular patient's seizures, and to curtail long hospital stays and use of EDs [21,22,39]. Patients should bring their rescue medications with them when visiting an outpatient clinic, and clinic staff should keep rescue medications in emergency crash carts in the epilepsy clinic when possible.

4. Style and content of the ASAP

ASAPs should be individualized to patients with customized information (Table 3 [17,37]).

ASAPs should be concise and easy to use, with the same elements incorporated regardless of patient age. Pediatric plans should incorporate doses of rescue medication based on weight. Rescue modalities or preferences may change with age or market availability, so specific choices should be clear, and revisions made when appropriate. An easy-to-use format is essential for reducing confusion when patients and caregivers may be anxious or upset about seizure episodes.

5. When to use the ASAP

Directions for what to do when an emergency occurs should be a key priority in the ASAP. Basic seizure safety should be noted (e.g., position the patient on his/her side, do not put anything in the patient's mouth). The plan's core should include simple instructions about when to

- Call the patient's neurology provider
- Give a medication (e.g., prolonged seizures lasting >5 min and >2 seizure clusters, upon onset of an aura [when indicated], and during seizure clusters)

Table 3

Patient information that can be customized in an acute seizure action plan [17].

- Patient-specific circumstances (e.g., seizure type, geographic location, home type)
- Emergency contact information (e.g., physician, family)
- How to recognize the patient's usual seizure signs and symptoms and know when a seizure is atypical [44]
- · How and when to administer seizure first aid to the patient
- Prescribed treatment information with step-by-step instructions for administration
- How to address the patient's seizure event milestones, such as when to start medication or when to transition to contacting emergency assistance (e.g., based on time intervals, such as medical intervention after ≥5 min of seizure episode) [37]
- When the patient's seizure event is an emergency and what to do

- Repeat medication (e.g., after a time period specified by the manufacturer's label or directed by evolving published evidence) [40–42]
- Call 911 (timing should be per the patient's ASAP)
- Go to the ED (e.g., if the seizure continues for a defined time period, repeats, or if there is a serious injury or persistent cyanosis)

An ASAP should be used to address any seizure and to address specific interventions ranging from basic first aid to rescue medications and calling for assistance [2]. The user needs to know the patient's usual seizure pattern, when intervention is necessary, and what to do after treatment [43]. Specifically, the ASAP should delineate parameters and directions for use of prescription rescue treatment [2,17].

The ASAP will empower the patient and caregiver [29]. It can educate and allow effective recognition of usual versus unusual patterns [39,44]. Injury risk assessment and prevention strategies [45] may be addressed by the ASAP. The ASAP may provide guidance in isolated geographic areas [37], in assisted living facilities [37], and for pre-hospital emergency personnel [39].

If the patient is not responsive, the ASAP may provide directions for determining whether the patient is unconscious or postictal. Guidance for care and medication administration if the patient is unconscious may be outlined.

6. Format of ASAP

An ASAP should improve the patient's quality of life and sense of empowerment to manage epilepsy. The ASAP format should reflect the need to decrease the burden of seizures for patient and caregiver, as well as for the doctor or nurse, by addressing issues specific to the individual patient. The ASAP should also be understandable to anyone (e.g., if babysitter needs to use it) and easily accessible in an emergency.

ASAP formats should be easily revisable. The majority of current ASAPs are paper forms, which are often redundant, too detailed, and too lengthy. Many current forms are either too general or too rigid, without easily modifiable formats. Because of these problems, they are often not used at all. Innovation to make the ASAP relevant to patient needs is necessary. Use of rescue plans for patients with other medical conditions may serve as models.

The ASAP should be dated to document its most current state. The content should be clearly presented and understandable to the widest possible range of caregivers with the least knowledge of epilepsy, so it can be implemented quickly in any rescue situation and in an ED. There should be clear step-by-step instructions specific to situations that the patient is likely to encounter. For example, the ASAP could include flowcharts or a decision tree based on individual circumstances (e.g., one example of an explicit flow diagram is shown in Fig. 1) [22].

An ASAP could make use of graphics, which may be more easily and quickly understandable than words in a hurried, stressful situation. For example, caregivers may find it helpful to refer to a graph of a seizure that shows when to intervene. A color-coded plan also may be easy to read and reference (e.g., stoplight imagery: green, under control and no/minimal action required; yellow, implement appropriate protocol; red, implement appropriate emergency protocol) [14,21]. Similar designs have been used for asthma patients [46]. An example of a potential ASAP format and graphics/color coding is provided in Fig. 1. This is one example of an ASAP that is adaptable. The HCP should ensure that the final ASAP format is appropriate for the individual patient.

An electronic ASAP may be more efficient than one only available on paper. An electronic plan would be available throughout a healthcare system through electronic medical records, third-

Acute Seizure Action Plan

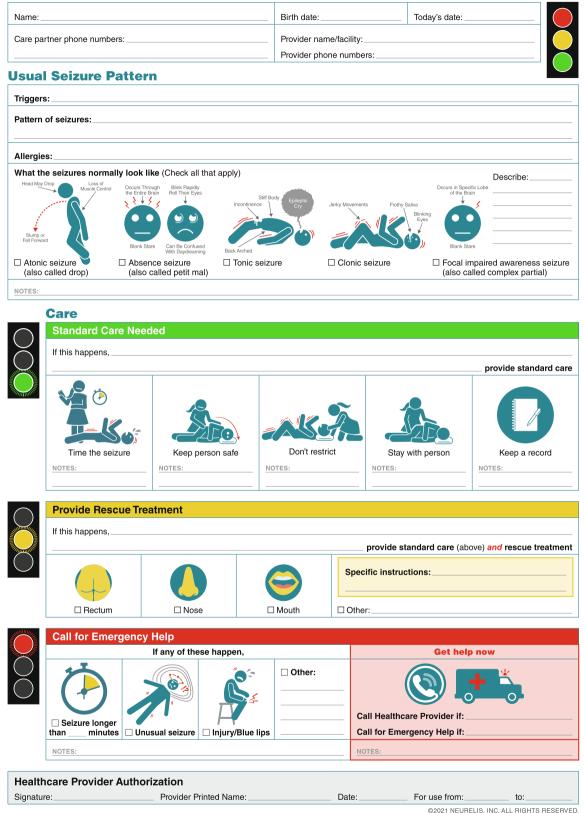


Fig. 1. One example of a simplified acute seizure action plan.

party sources, and patient portals, allowing for visualization from smartphones, tablets, and other devices. Electronic ASAPs can be easily updatable, making them more modifiable than paper forms alone, and transmission to other providers in other systems would be expedited. A paper version could be downloaded for home use or be carried by the patient. A common format that would translate to the myriad of electronic systems would be ideal. As an example, the Epilepsy Foundation has downloadable versions of its electronically fillable SAP with versions for everyone and for school use at the following URL: https://www.epilepsy.com/liv-ing-epilepsy/toolbox/seizure-forms. However, such forms may not be easily accessible from a patient's medical record during a clinic visit.

Online links [22] and mobile applications also have been used for ASAPs. As an example, a more detailed and longer management application may include a seizure diary, medication diary, education, emotion management, test results, and a survey [47]. A smartphone application may allow for automatic functions (e.g., notifying a designated person or physician or displaying the ASAP). A mobile application could include an audio component, such as detailed voice instructions. Tablet applications have also been studied [16]. One limitation of these types of electronic ASAPs is that they would need to be usable by people who may not be comfortable with the technology, and in the stress of an emergency situation, they may not be used. Also, the devices for use of ASAP applications will need to be portable and available across socioeconomic strata.

In summary, an ASAP should be brief (1-2 pages), use simple wording (e.g., sixth-grade level), be concise, and be easy to follow. Pictures may be helpful (e.g., images of the patient's medications) to ensure clarity for the patient or caregiver.

Finally, potential ancillary items could be provided with the ASAP to help the patient and caregiver remember what needs to be done. Examples include a refrigerator magnet with proper dosing administration information [21] and a seizure preparedness wallet card that can be distributed.

7. Conclusions

Approximately 70% of persons with epilepsy do not have an SAP, even though SAPs can be helpful for all patients. In the authors' opinion there are limitations to currently available SAPs. Few focus on the immediate recognition of and early preventative treatment of an evolving seizure emergency. There is not a consistent format recommended in the literature.

In this paper, our group of experts offers guidance on appropriate ASAP development, content, and use during an acute seizure emergency. The recommended easy-to-use but comprehensive and individualized ASAP will empower patients and caregivers and diminish seizure burden, fear, and hospitalization. It also will minimize the burden of HCPs and reduce healthcare utilization costs and ED visits. Input and validation from patients, HCPs, and advocacy groups will be important in moving forward with ASAP development that addresses the concerns of all stakeholders involved.

The concept for this paper originated at a meeting of the Neurosciences Council that was convened in February 2020 with financial support from Neurelis. During its closed-door meeting, the Council discussed current ASAPs and opportunities for improvement. The Council resolved to produce a paper presenting the agreed upon expert opinion recommendations on ASAP development, use, content, and format.

8. Disclosures

Dr. Penovich has served on speakers' bureaus for GW Pharmaceuticals; Neurelis, Inc.; SK Life Science; and UCB, and is an advisor to Engage Therapeutics; LVIS Corporation; Neurelis, Inc.; and SK Life Science. **Dr. Glauser** is a consultant for Clarigent Health; Eisai Inc.; Neurelis, Inc.; Supernus Pharmaceuticals, Inc; and UCB. He receives research support from the National Institutes of Health. Dr. Becker is a speaker for Neurelis, Inc; SK Life Science; Supernus, Inc; and Neuropace, Inc, and is an advisor for Neurelis, Inc; SK Life Science; and Supernus, Inc. Dr. Patel receives research support from the National Institutes of Health and Pediatric Epilepsy Research Foundation; receives institutional research support from Stoke; receives compensation for being a member of the Greenwich Biosciences Education Content Workgroup; is an advisor for Neurelis, Inc; and receives compensation for webinar development from Medscape and Neurology Live. Dr. Sirven is an advisor for Neurelis, Inc. Ms. Long is a consultant for Neurelis, Inc.; SK Life Science; and Supernus Pharmaceuticals, and is a speaker for Liva-Nova. Dr. Stern is a consultant for Eisai; Neurelis, Inc.; SK Life Science; and UCB. Dr. Dixon-Salazar is a consultant for the LGS Foundation, the Chan Zuckerberg Initiative and Neurelis, Inc. Dr. Carrazana is an employee of and has received stock and stock options from Neurelis. Inc. Dr. Carrazana has received compensation for serving on the boards of directors of Marinus and Hawaii-Biotech. Dr. Rabinowicz is an employee of and has received stock options from Neurelis, Inc.

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