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American Academy of
Physical Medicine and Rehabilitation

AAPM&R SPASTICITY SUMMIT:
DECEMBER 6, 2022

HILTON ROSEMONT/CHICAGO O'HARE

Removing Barriers with Real Solutions to Improve Patient Care

COMMITTED TO THE ISSUES IMPORTANT TO OUR PATIENTS

CARE ACCESS, PATIENT AND CAREGIVER SUPPORT, & CLINICAL CAPACITY AND CAPABILITY

AAPM&R Spasticity Summit: Care Access, Patient and Caregiver Support, & Clinical Capacity and Capability | December 6, 2022

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MEETING OVERVIEW

On December 6, 2022, a select group of physical medicine and rehabilitation (PM&R) physicians, clinical experts, patient advocates, and organization or industry representatives participated in the AAPM&R Spasticity Summit workshop to discuss the barriers and potential solutions for improved care and support for spasticity patients. In advance of the Summit, attendees were surveyed about their perception of the importance of key issues to be discussed during the Summit. In an expert discussion led by Christina Kwasnica, MD, FAAPMR and Atul Patel, MD, MHSA, FAAPMR, AAPM&R Treasurer, perspectives and insights on specific barriers to treatment for spasticity patients and solutions to those barriers were exchanged. Three key issues were addressed during two breakout discussion sessions of participants: 1) care access for patients, 2) patient and caregiver support, 3) and clinical capacity and capabilities. The first breakout session focused on prioritizing barriers to spasticity care, and the second breakout session focused on prioritizing solutions that will have the greatest impact in addressing barriers. Important points from the Summit are outlined below.

BACKGROUND

Spasticity causes significant functional impairment and can reduce the quality-of-life for afflicted individuals. Access to adequate care is one of the main challenges facing spasticity patients. In the U.S., many individuals do not live in areas where hospitals and clinics offer treatment for spasticity. Barriers to access may also include financial burdens for patients, which can preclude potential treatment options. Patient and caregiver support is also a fundamental component of quality spasticity care. Caring for individuals with spasticity can be challenging and stressful. Fears of inadequate care and financial concerns can negatively impact the well-being of caregivers and their patients. Clinic capacity and capability are vital considerations for the quality of spasticity care. Difficulties in diagnosing and managing spasticity patients can reduce quality care and delay necessary treatment. The successful rehabilitation of patients relies on hospitals and clinics with multidisciplinary teams skilled in treating individuals with spasticity.

PROGRAM OBJECTIVES

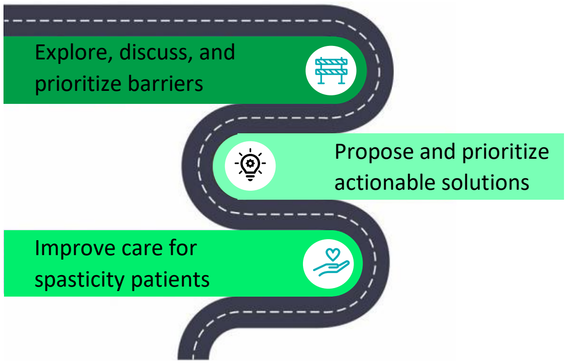
- Explore, discuss and prioritize barriers within three key areas of patient care that, if solved, will have the greatest impact on addressing gaps in spasticity care:

  - Access to care

  - Patient and caregiver support

  - Clinical capacity and capabilities

- Evaluate priorities and reach a consensus regarding identified barriers in the three key areas.
- Propose, discuss and prioritize actionable solutions that will have the greatest impact on addressing the barriers identified in the three key areas.
- Evaluate priorities and reach a consensus on actionable solutions for the identified barriers in the three key areas.



To meet these objectives, Spasticity Summit Co-Chairs presented the current state of spasticity and reviewed key findings of the research paper in development. Conversations and questions about the research paper and the identification of treatment gaps for spasticity patients were discussed. These presentations provided a platform for breakout sessions for participants to discuss barriers and potential solutions for the care of spasticity patients.

The goal of the AAPM&R Spasticity Summit is to define the U.S. healthcare's high-priority barriers related to spasticity care that can lead to a three-to-five-year plan to implement identified solutions and a publication of the consensus-building process. AAPM&R is taking a leadership role to address this crucial issue in healthcare by taking the initial step of convening key stakeholders and leaders in spasticity assessment and treatment.

ATTENDEES

Speakers and Moderators

Steven Flanagan, MD, FAAPMR, AAPM&R President
Chair of Rehabilitation Medicine at NYU School of Medicine
Rusk Rehabilitation at NYU Langone Health

Christina Kwasnica, MD, FAAPMR
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Participating Organizations

The American Academy of Physical Medicine and Rehabilitation (AAPM&R)
AAPM&R is the premier medical society for the specialty of physical medicine and rehabilitation (PM&R), exclusively serving the needs of approximately 9,000 physical medicine and rehabilitation physicians (also known as physiatrists) primarily throughout the United States. PM&R is the medical specialty dedicated to maximizing physical function and quality-of-life. Each year, people who have experienced a wide range of conditions and related symptoms—including, but not limited to, traumatic brain injury, stroke, pain and spasticity—are treated by PM&R physicians. AAPM&R employs 42 experienced, dedicated staff members who work alongside volunteers to carry out the focus, mission and vision of the Academy.

AbbVie
AbbVie's mission is to discover and deliver innovative medicines that solve serious health issues today and address the medical challenges of tomorrow. AbbVie strives to have a remarkable impact on people's lives across several key therapeutic areas.

American Academy of Family Physicians (AAFP)
Founded in 1947, the American Academy of Family Physicians (AAFP) represents family physicians, residents and medical students nationwide. It is the only medical society devoted solely to primary care. Our vision is to transform healthcare to achieve optimal health for everyone. Our mission is to improve the health of patients, families and communities by serving the needs of our members with professionalism and creativity.

American Academy of Neurology (AAN)
The American Academy of Neurology (AAN), established in 1948, is an international professional association with more than 38,000 neurologists and neuroscience professionals dedicated to providing the best possible care for patients with neurological disorders. The AAN is strongly committed to its mission and focuses its efforts on ensuring the reality of the principles and standards set forth in the AAN mission statement.

American Geriatrics Society (AGS)
The American Geriatrics Society (AGS) is a not-for-profit organization of nearly 6,000 health professionals devoted to improving the health, independence and quality-of-life of all older people. The Society provides leadership to healthcare professionals, policy makers and the public by implementing and advocating for programs in patient care, research, professional and public education and public policy.

American Stroke Association
The American Stroke Association is a relentless force for a healthier world with fewer strokes — the No. 2 cause of death worldwide and a leading cause of disability. As champions for health equity, we commit to identify and remove barriers to healthcare access and quality and advance cardiovascular health for all. A stroke is a life-changing event — physically and emotionally. Every stroke is unique, and so is every recovery. As a trusted resource, look to us for the latest evidence-based information on stroke, post-stroke recovery, caregiver tools and resources and education for healthcare professionals.

American Physical Therapy Association (APTA)
The American Physical Therapy Association is a national professional organization representing more than 100,000 members which seeks advancements in physical therapy practice, research, and education. Our mission is to build a community that advances the profession of physical therapy to improve the health of society.

Blue Cross Blue Shield Association
Blue Cross Blue Shield Association is a national federation of 34 independent, community-based, and locally operated Blue Cross and Blue Shield companies that collectively provide healthcare coverage for one in three Americans. BCBSA provides healthcare insights through The Health of America Report series and the national BCBS Health Index.

Brain Injury Association of America (BIAA)
The Brain Injury Association of America (BIAA) is the Voice of Brain Injury. We are dedicated to increasing access to quality healthcare and raising awareness and understanding of brain injury through advocacy, education and research. With a nationwide network of state affiliates, local chapters and support groups, we provide help, hope, and healing to individuals who live with brain injury, their families, and the professionals who serve them.

Illinois Association of Medicaid Health Plans (IAMHP)
Illinois Association of Medicaid Health Plans (IAMHP) is a membership organization of health plans that participate in Medicaid managed care in Illinois. Our members are committed to improving the health of Illinoisans through high-quality healthcare that effectively and efficiently meets the needs of patients.

Ipsen Biopharmaceuticals
Ipsen is a global specialty-driven biopharmaceutical group focused on innovation and Specialty Care. It develops and commercializes innovative medicines in three key therapeutic areas – Oncology, Neuroscience and Rare Disease. Neuroscience is advancing at an unprecedented rate and Ipsen is at the forefront of this transformation.

Medtronic
A global healthcare technology leader — boldly attacking the most challenging health problems facing humanity with innovations that transform lives.

Merz Therapeutics
At Merz Therapeutics, a part of the Merz Pharmaceuticals GmbH and family owned Merz Group, our dedication to helping patients achieve their individual goals is as much our legacy as it is our vision for the future. We seek to address the unique needs of people who suffer from movement disorders, neurological conditions and other health conditions that severely impact patients' quality-of-life. This spirit drove us to become one of the first companies to develop and commercialize botulinum toxin. With our cutting-edge research and development efforts, highly-scientific medical affairs resources and dedicated commercial teams, we continue the advancement of new and individualized treatment standards.

SUMMIT AGENDA

Time (CT)	Topic
7:30-8 am	Continental Breakfast
8-8:05 am	Welcome/Call to Order
8-8:15 am	Pre-Summit Survey Results
8:15-8:45 am	Summit Attendee Introductions
8:45-9:50 am	Current State of Spasticity: Presentation and Discussion
9:50-9:55 am	Breakout Session #1: Overview for Attendees
9:55-10:10 am	Break/Move to assigned breakout rooms
10:10-11:55 am	Breakout Session #1/Report Out *GOAL: Prioritize the top three barriers that, if solved, will have the greatest impact in addressing gaps in spasticity care.* 60-minute discussion; 5 minutes reassemble; 30-minute report out; 10-minute reflections from chairs
11:55 am-12:55 pm	Lunch
12:55-1 pm	Reconvene/ Breakout Session #2: Overview for Attendees
1-1:05 pm	Move to assigned breakout rooms
1-2:50 pm	Breakout Session #2/Report Out *GOAL: Identify five to seven solutions that will have the greatest impact in addressing the top three barriers identified in Breakout Session #1.* 60-minute discussion; 5 minutes reassemble; 30-minute report out; 10-minute reflections from chairs

2:50-3:05 pm	Break
3:05-3:40 pm	Full Group Discussions: Consensus on Solutions *GOAL: Rank solutions to identified barriers*
3:40-3:50 pm	Reflections & Next Steps
3:40-4 pm	Conclusion and Farewell

Pre-Summit Survey

Prior to the Summit, attendees were asked to prioritize specific barriers to the various aspects of spasticity care that were proposed by the Summit committee. Attendees also put forth additional barriers as write-ins. The survey focused on three main topics of spasticity care: access to care, patient and caregiver support, and clinical capacity and capabilities.

Breakout Sessions

There were two, 1-hour breakout sessions with a Summit facilitator, a reporter to take notes, and approximately 10 attendees in each group. The reporter provided a 10-minute report-out to all attendees at the conclusion of each breakout session. The three key issues were the same for both breakout sessions, but the objectives differed. Breakout groups were preassigned into mixed groups that addressed one of the three key issues listed above. These groups included a balanced representation of attendees from PM&R organizations, clinical experts and industry representatives.

Breakout Session #1: Prioritize Barriers

This breakout session focused on barriers to three key issues: patient care access, patient and caregiver support, and clinical capacity and capability. The attendees discussed and prioritized the thought-starter questions from the pre-Summit survey regarding barriers as the primary focus of the session but were not necessarily limited to the topics provided. Barriers added as write-ins during the survey process were also considered. The attendees in each group were to rank the top three barriers in each of the three key areas of spasticity care.

Breakout Session #2: Prioritize Solutions to Barriers

This breakout session focused on solutions to identified barriers for three key issues: patient care access, patient and caregiver support, and clinical capacity and capability. The attendees discussed and prioritized five to seven actionable solutions to the top three identified barriers from Breakout Session #1 as the primary focus of the session.

Full Group Discussion

Attendees took part in a full group discussion with the goal of coming to a consensus on priorities of actionable solutions to barriers. The group discussions were designed to identify trends among those with similar roles and points of view. Attendees were asked to prioritize solutions identified from Breakout Session #2, indicating priority to a solution by placing a dot on the idea presented. Attendees were to place nine dots on any solution in any area and could place more than one dot on a particular idea if desired. In addition, attendees were to place one star on any area they felt was the most important. The dots were colored to indicate attendee affiliation: pink representing clinicians and healthcare providers, orange representing patient advocates, and green representing industry and payer representatives.

> *"We value bringing a diverse group of people together and we've done that today...without this diversity, we really can't do what we need to do. We have lots of talent and skill in this room...The whole idea is that we are going to collaborate moving forward with this Summit today."*
>
> **Steven Flanagan, MD, FAAPMR, AAPM&R President**

KEY TAKEAWAYS

- **Prior to the conversation in a pre-Summit survey, attendees were asked to prioritize specific barriers to various aspects of spasticity care that were proposed by the Summit committee and additional barriers were put forth by attendees. The survey focused on three main topics of spasticity care: access to care, patient and caregiver support, and clinical capacity and capabilities. Out of 29 participants, there were 27 completed and two partially completed surveys. The survey questions, responses, and priority ranking, expressed as #1 (highest priority) to #6 or #7 (lowest priority), are as follows:**

Access to Care: Please rank the following based upon your knowledge and experience, which areas must be addressed by U.S. healthcare to address the access to care challenges for spasticity. Please rank them from most important (1) to least important (6).

#1: DOCUMENT THE ACCESS CHALLENGE: Document the extent and impact of the access challenge (definitive research into the percent of patients treated, cost/benefit ratio, pain related to spasticity, caregiver burden, other measures).

Weighted Average: 13.6

Rank	1	2	3	4	5	6
# of Responses	13	5	0	5	5	0

#2: IMPROVE GEOGRAPHIC PROVIDER COVERAGE: Improve access to appropriate care in geographic locations that lack enough providers who treat spasticity.

Weighted Average: 16.0

Rank	1	2	3	4	5	6
# of Responses	4	8	9	2	5	0

#3: ENSURE ENVIRONMENT OF INCENTIVES: Ensure a favorable regulatory and business/industry environment that incentivizes all stakeholders (i.e., providers, payers, etc.) to help increase care access.

Weighted Average: 18.0

Rank	1	2	3	4	5	6
# of Responses	3	8	5	4	8	0

#4: INCREASE ACCESS FOR UNISURED AND UNDERINSURED: Help underinsured and uninsured individuals with spasticity to access care.

Weighted Average: 20.0

Rank	1	2	3	4	5	6
# of Responses	4	4	3	8	7	2

#5: INCREASE ACCESS FOR UNDERSERVED: Improve access to appropriate care for underserved demographic groups.

Weighted Average: 21.8

Rank	1	2	3	4	5	6
# of Responses	0	2	10	9	3	4

#6: Other: Write-In Responses:

- ARTICULATE AAPM&R CARE STANDARDS: AAPM&R Guidelines for standards of care, protocols of first-line treatment.

- ESTABLISH CONTINUUM OF CARE TO ENSURE HCP FOLLOW UP: Ensure a continuum from acute initial phase of underlying disease (e.g., stroke) to appearance of symptoms so HCPs providing follow-up are on the lookout and refer patient as needed.

- INCREASE ACCESS IN INSTITUTIONAL SETTINGS: Improve access to care in institutions that lack PM&R physicians who treat spasticity (i.e., long-term care, SNFs, nursing homes).

- IMPROVE TRANSPORT SERVICES: Improve transport services in communities for patients lacking transportation to clinical services.

- INCREASE ACCESS TO HIGH-TECH/RESTRICTED MEDICATIONS: Access to high-tech interventions for spasticity (e.g., Baclofen pump, Botox injections) and to more expensive/restricted medications.

- IMPROVE PATIENT START: Improve appropriate patient start, including starting dose.

- COORDINATION AMONG SPECIALITIES: Coordination and awareness of spasticity with various medical specialties.

Patient and Caregiver Support: Please rank the following based upon your knowledge and experience, which areas must be addressed by U.S. healthcare to address the patient and caregiver support challenges for spasticity. Please rank them from most important (1) to least important (7).

#1: INCREASE CAREGIVER/COMMUNITY AWARENESS: Improve caregiver and community awareness of spasticity.

Weighted Average: 12.2

Rank	1	2	3	4	5	6
# of Responses	12	4	4	3	1	4

#2: IMPROVE PATIENT CAPABILITY TO FOLLOW CARE PLAN: Increase ability for people with spasticity to follow their care plan, including those who are cognitively impaired.

Weighted Average: 12.7

Rank	1	2	3	4	5	6
# of Responses	4	9	8	2	2	2

#3: GREATER ACCESS TO PHYSICAL SUPPORT: Provide those with spasticity greater access to appropriate physical support.

Weighted Average: 14.3

Rank	1	2	3	4	5	6
# of Responses	6	6	4	6	4	2

#4: IMPROVE SUPPORT FOR UNTRAINED PATIENTS/CAREGIVERS: Improve support and resources for untrained patients and caregivers of people who have spasticity.

Weighted Average: 16.3

Rank	1	2	3	4	5	6
# of Responses	3	3	9	5	6	2

#5: EQUIP PATIENTS/CAREGIVERS FOR ADVOCACY: Equip patients and caregivers to advocate for people with spasticity.

Weighted Average: 20.0

Rank	1	2	3	4	5	6
# of Responses	2	4	1	7	5	9

#6: OPTIMIZE MENTAL/EMOTIONAL HEALTH: Optimize mental and emotional health for people with spasticity.

Weighted Average: 22.3

Rank	1	2	3	4	5	6
# of Responses	0	2	2	5	10	9

#7: Other: Write-In Responses:

- EDUCATE REHAB SPECIALISTS: Further education for rehab specialists on how to effectively treat and manage spasticity.

- BOOST INSURANCE COVERAGE FOR CAREGIVING: Insurance coverage for respite care, caregiver support, transportation.

- DEVELOP PATIENT/CAREGIVER EDUCATIONAL MATERIAL: Provide high-quality educational material to patients, families, and caregivers on spasticity and available treatments.

- DEEPEN UNDERSTANDING OF TREATMENT OPTIONS: Greater understanding of all treatment options and timing.

- INCREASE SPASTICITY AWARENESS AMONG CLINICIANS: Awareness of spasticity across the medical specialties.

Clinical Capacity and Capabilities: Please rank the following based upon your knowledge and experience, which areas must be addressed by U.S. healthcare to address the clinical capacity and capabilities challenges for spasticity. Please rank them from most important (1) to least important (7).

#1: EDUCATE CLINICIANS REGARDING PATIENT NEEDS: Increase access to clinician education on how to assess and treat those with spasticity about the needs of those with spasticity (i.e., how to treat and manage cases in an outpatient vs. institutional setting).

Weighted Average: 11.7

Rank	1	2	3	4	5	6
# of Responses	9	8	5	1	4	1

#2: IMPROVE DIAGNOSIS: Improve the diagnosis of spasticity in those with stroke, TBI, and SCI.

Weighted Average: 14.5

Rank	1	2	3	4	5	6
# of Responses	8	4	3	7	2	4

#3: ENSURE ENVIRONMENT OF INCENTIVES: Ensure a favorable regulatory and business environment that incentivizes providers.

Weighted Average: 17.3

Rank	1	2	3	4	5	6
# of Responses	5	7	3	2	4	8

#4: INCREASE CASE FOLLOW-UP INCIDENCE: Increase the incidence of spasticity case follow-up by appropriate providers.

Weighted Average: 17.3

Rank	1	2	3	4	5	6
# of Responses	5	2	3	7	8	4

#5: IMPROVE TREATMENT OPTIONS: Improve the implementation of interventional treatment options (i.e., botulinum toxin injections, intrathecal baclofen pumps) in clinical workflows.

Weighted Average: 18.3

Rank	1	2	3	4	5	6
# of Responses	0	4	9	7	1	6

#6: CLARIFY PROFESSIONALS' ROLES: Clarify the roles and challenges of various health professionals in expanding care for those with spasticity.

Weighted Average: 19.3

Rank	1	2	3	4	5	6
# of Responses	0	5	5	4	9	5

#7: Other: Write-In Responses:

- ARTICULATE STANDARD OF CARE: Protocol spasticity treatment guidelines published by national organizations for clinicians to become standard of care.

- IMPROVE INCENTIVES FOR PROVIDERS: Industry can train physicians, but there needs to be incentives for these providers to want to be in this space. Need to make sure that spasticity management is a field that providers want to enter.

- REDUCE TIERED APPROACH: Reduce the perception that spasticity treatment should be provided in a tiered approach.

- INCREASE COORDINATION BETWEEN PROVIDERS: Coordination between providers for comprehensive care.

- **Priorities and consensus from Breakout Session #1 showed that the majority of attendees in each group agreed the top three barriers, ranked from most important (1) to least important (3), for the three key areas are as follows:**

Access to Care:

#1: Document the extent and impact of the access challenge.
  - ✓ Stronger evidence would improve access
  - ✓ Broaden the diagnosis beyond just stroke; encompass all upper motor neuron (UMN) injuries
  - ✓ Problem is getting bigger with time–evidence should demonstrate urgency
  - ✓ Possibly harness existing databases/patient registries to provide evidence

#2: Guidelines for standard of care
  - ✓ Articulate the care standards to improve care quality
  - ✓ Need to increase the focus on outcomes (e.g., functionality) and good outcome measures

#3: Ensure a favorable regulatory and business/industry environment that incentivizes all stakeholders (e.g., providers, payers, etc.) to help increase care access.
  - ✓ Ensure an environment of incentives
  - ✓ RVS Update Committee (RUC) advocacy to increase reimbursement for complex spasticity management, especially with intrathecal baclofen therapy (ITB)
  - ✓ Insurance plans would perform cost/savings analysis demonstrating lowered overall cost of care with ITB

Additional #4: Increase providers that treat spasticity (e.g., physiatrists, neurologists, advanced practice providers) and increase training programs on how to run a spasticity practice.

Patient and Caregiver Support:

#1: Improve caregiver and community awareness of spasticity and spasticity treatments for the purpose of patient/caregiver empowerment.

- ✓ Develop high-quality patient/caregiver educational materials about spasticity and available treatments
- ✓ Improve support for untrained patients/caregivers (financial and beyond)
- ✓ Equip patients/caregivers for advocacy (community, church, social groups empowering individuals)

#2: Increase ability for people with spasticity to follow their care plan across all racial and ethnic groups, including those individuals who are cognitively impaired.

- ✓ Provide financial support (insurance coverage) for respite care, caregiver support and home healthcare training, and transportation
- ✓ Provide greater access to physical support (ramps, transportation, patient aids and nurses)
- ✓ Optimize mental and emotional health for people with spasticity and caregivers

Clinical Capacity and Capabilities:

#1: Increase access to clinician education on how to assess and treat those with spasticity about the needs of those with spasticity (i.e., how to treat and manage cases in an outpatient vs. institutional setting).

- ✓ Educate clinicians regarding patient needs
- ✓ Stratified Center of Excellence (CoE): not every community/geography can offer the same treatments; need conceptual markers
- ✓ Need standards that provide guidance but allow flexibility for providers to be a CoE that routes patient to appropriate care, regardless of geography or resources
- ✓ Multiple disciplines and stakeholders are involved in this process

#2: Protocol spasticity treatment guidelines published by national organization for clinicians to become standard of care.

- ✓ Automatic specialty follow-up
- ✓ Tiered approach when useful
- ✓ Clarify roles and challenges (challenges may be common or unique and sometimes related to geography)
- ✓ Include advanced treatments (Tx)

#3: Incentive for providers to want to be in this space. Need to make sure that spasticity management is a field that providers want to enter.

- ✓ Financial incentives
- ✓ Improved quality-of-lifestyle incentives for providers (beyond financial incentives)
- ✓ Favorable regulatory and business environments
- ✓ Greater financial resources
- ✓ Workforce issues: 12,000 PM&R physicians but only 25% of those treat spasticity and movement disorders

- **Priorities, consensus, and rankings from Breakout Session #2 showed that the majority of attendees in each group agreed the importance of key areas and the top five to seven solutions to address barriers for the three key areas are as follows:**

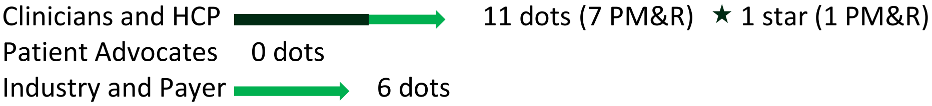
<u>Access to Care (Total votes per key area):</u>

<u>Patient and Caregiver Support (Total votes per key area):</u>

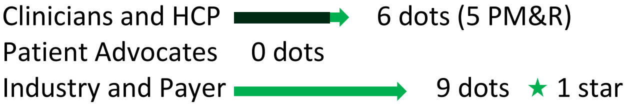
<u>Clinical Capacity and Capabilities (Total votes per key area):</u>

<u>Access to Care (Total votes per solution):</u>

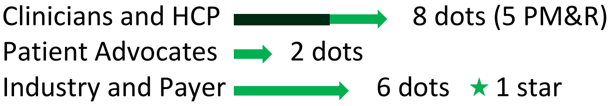
#1: Demonstrate with evidence that overall cost of healthcare can be lowered with appropriate spasticity treatment.



#2: Improve articulation of care standards (Academy white paper).



#3: Improve reimbursement for spasticity management.



#4: Increase providers who can offer spasticity management/increase workforce.
Clinicians and HCP 9 dots (8 PM&R)
Patient Advocates 2 dots
Industry and Payer 11 dots

#5: Improve coding and referral practices for spasticity-related diagnoses.
Clinicians and HCP 4 dots (3 PM&R) ★ 1 star
Patient Advocates 2 dots
Industry and Payer 1 dot

<u>Patient and Caregiver Support (Total votes per solution):</u>

#1: Assessment of currently available resources (informational resources, educational, e.g., stroke.org/spasticity)
Clinicians and HCP 9 dots (5 PM&R)
Patient Advocates 2 dots
Industry and Payer 5 dots

#2: Identify and organize a "home base" for spasticity
Clinicians and HCP 6 dots (5 PM&R) ★★★★ 4 stars (3 PM&R)
Patient Advocates 2 dots ★★ 2 stars
Industry and Payer 5 dots ★★ 2 stars

#3: Create spasticity coalition ("home base") website linked to multiple channels/other organizational websites.
Clinicians and HCP 6 dots (3 PM&R) ★★ 2 stars (2 PM&R)
Patient Advocates 0 dots
Industry and Payer 7 dots ★ 1 star

#4: Education
Clinicians and HCP 12 dots (6 PM&R)
Patient Advocates 2 dots
Industry and Payer 17 dots

<u>Clinical Capacity and Capabilities (Total votes per solution):</u>

#1: Develop, publish, and disseminate a white paper/consensus guidance statement.
Clinicians and HCP 9 dots (8 PM&R) ★★★★★ 5 stars (2 PM&R)
Patient Advocates 2 dots
Industry and Payer 7 dots ★★★★★★ 6 stars

#2: Create an evidence generation plan aggregating data across all spasticity organizations for consensus with a systematic review of the data gathered.
Clinicians and HCP 8 dots (5 PM&R)

Patient Advocates ➡ 2 dots
Industry and Payer ➡ 10 dots

#3: Mobilize local PM&R champions (physiatrists, local organizations) to address and advance issues in spasticity in local institutions and communities.
Clinicians and HCP ➡ 2 dots (2 PM&R)
Patient Advocate 0 dots
Industry and Payer ➡ 2 dots

#4: Improve continuation of care by working with primary care physicians and other stakeholders to create win-win workflows for patients with spasticity.
Clinicians and HCP ➡ 14 dots (9 PM&R)
Patient Advocates ➡ 2 dots
Industry and Payer ➡ 5 dots ★ 1 star

#5: Create a "Center of Excellence" program to recognize providers of spasticity care.
Clinicians and HCP ➡ 5 dots (5 PM&R) ★ 1 star (1 PM&R)
Patient Advocates 0 dots
Industry and Payer ➡ 5 dots

DISCUSSION SUMMARY

Welcome/Call to Order

AAPM&R President, Steven Flanagan, MD, FAAPMR, began the program by welcoming attendees, speakers and guests of the Summit. Dr. Flanagan provided an overview of the day's agenda and thanked the supporters of the Spasticity Summit and the planning committee. He highlighted the collaborative nature of the Summit and invited attendees to ask questions and actively participate in discussions throughout the day. Dr. Flanagan emphasized the value of diverse group composition to enhance innovative thinking and achievement. He discussed the importance of mutual respect among members of differing opinions and viewpoints. Dr. Flanagan expressed he hoped the Summit would cultivate a receptive space for positive contributions from diverse experience, talent and knowledge.

Pre-Summit Survey Results

Doug Diefenbach, Spasticity Summit Facilitator, presented the Summit agenda and the results from the pre-Summit survey taken by attendees. Mr. Diefenbach began by summarizing the goal of the Summit: to define high-priority barriers related to spasticity care and identify potential solutions. He described that discussions would be structured to build consensus on the top barriers, that if solved, will have the greatest impact in addressing gaps in spasticity care and identify actionable solutions to address the priority barriers. Mr. Diefenbach also outlined the conversation format of shared individual perspectives, acknowledgement of all views and participation in the consensus-building process. He continued by reviewing the day's Summit agenda and process, the grouping of attendees and individual roles. Mr. Diefenbach then shared the pre-Summit survey questions and reviewed results of the prioritization of barriers and write-ins.

The pre-Summit survey results are as follows:

Access to Care: Please rank the following based upon your knowledge and experience, which areas must be addressed by U.S. healthcare to address the access to care challenges for spasticity. Please rank them from most important (1) to least important (6).

#1: DOCUMENT THE ACCESS CHALLENGE: Document the extent and impact of the access challenge (definitive research into the percent of patients treated, cost/benefit ratio, pain related to spasticity, caregiver burden, other measures).

Weighted Average: 13.6

Rank	1	2	3	4	5	6
# of Responses	13	5	0	5	5	0

#2: IMPROVE GEOGRAPHIC PROVIDER COVERAGE: Improve access to appropriate care in geographic locations that lack enough providers who treat spasticity.

Weighted Average: 16.0

Rank	1	2	3	4	5	6
# of Responses	4	8	9	2	5	0

#3: ENSURE ENVIRONMENT OF INCENTIVES: Ensure a favorable regulatory and business/industry environment that incentivizes all stakeholders (i.e., providers, payers, etc.) to help increase care access.

Weighted Average: 18.0

Rank	1	2	3	4	5	6
# of Responses	3	8	5	4	8	0

#4: INCREASE ACCESS FOR UNISURED AND UNDERINSURED: Help underinsured and uninsured individuals with spasticity to access care.

Weighted Average: 20.0

Rank	1	2	3	4	5	6
# of Responses	4	4	3	8	7	2

#5: INCREASE ACCESS FOR UNDERSERVED: Improve access to appropriate care for underserved demographic groups.

Weighted Average: 21.8

Rank	1	2	3	4	5	6
# of Responses	0	2	10	9	3	4

#6: Other: Write-In Responses:

- ARTICULATE AAPM&R CARE STANDARDS: AAPM&R Guidelines for standards of care, protocols of first-line treatment.

- ESTABLISH CONTINUUM OF CARE TO ENSURE HCP FOLLOW UP: Ensure a continuum from acute initial phase of underlying disease (e.g., stroke) to appearance of symptoms so HCPs providing follow-up are on the lookout and refer patient as needed.

- INCREASE ACCESS IN INSTITUTIONAL SETTINGS: Improve access to care in institutions that lack PM&R physicians who treat spasticity (i.e., long-term care, SNFs, nursing homes).

- IMPROVE TRANSPORT SERVICES: Improve transport services in communities for patients lacking transportation to clinical services.

- INCREASE ACCESS TO HIGH-TECH/RESTRICTED MEDICATIONS: Access to high-tech interventions for spasticity (e.g., Baclofen pump, Botox injections) and to more expensive/restricted medications.

- IMPROVE PATIENT START: Improve appropriate patient start, including starting dose.

- COORDINATION AMONG SPECIALITIES: Coordination and awareness of spasticity with various medical specialties.

Patient and Caregiver Support: Please rank the following based upon your knowledge and experience, which areas must be addressed by U.S. healthcare to address the patient and caregiver support challenges for spasticity. Please rank them from most important (1) to least important (7).

#1: INCREASE CAREGIVER/COMMUNITY AWARENESS: Improve caregiver and community awareness of spasticity.

Weighted Average: 12.2

Rank	1	2	3	4	5	6
# of Responses	12	4	4	3	1	4

#2: IMPROVE PATIENT CAPABILITY TO FOLLOW CARE PLAN: Increase ability for people with spasticity to follow their care plan, including those who are cognitively impaired.

Weighted Average: 12.7

Rank	1	2	3	4	5	6
# of Responses	4	9	8	2	2	2

#3: GREATER ACCESS TO PHYSICAL SUPPORT: Provide those with spasticity greater access to appropriate physical support.

Weighted Average: 14.3

Rank	1	2	3	4	5	6
# of Responses	6	6	4	6	4	2

#4: IMPROVE SUPPORT FOR UNTRAINED PATIENTS/CAREGIVERS: Improve support and resources for untrained patients and caregivers of people who have spasticity.

Weighted Average: 16.3

Rank	1	2	3	4	5	6
# of Responses	3	3	9	5	6	2

#5: EQUIP PATIENTS/CAREGIVERS FOR ADVOCACY: Equip patients and caregivers to advocate for people with spasticity.

Weighted Average: 20.0

Rank	1	2	3	4	5	6
# of Responses	2	4	1	7	5	9

#6: OPTIMIZE MENTAL/EMOTIONAL HEALTH: Optimize mental and emotional health for people with spasticity.

Weighted Average: 22.3

Rank	1	2	3	4	5	6
# of Responses	0	2	2	5	10	9

#7: Other: Write-In Responses:

- EDUCATE REHAB SPECIALISTS: Further education for rehab specialists on how to effectively treat and manage spasticity.

- BOOST INSURANCE COVERAGE FOR CAREGIVING: Insurance coverage for respite care, caregiver support, transportation.

- DEVELOP PATIENT/CAREGIVER EDUCATIONAL MATERIAL: Provide high-quality educational material to patients, families, and caregivers on spasticity and available treatments.

- DEEPEN UNDERSTANDING OF TREATMENT OPTIONS: Greater understanding of all treatment options and timing.

- INCREASE SPASTICITY AWARENESS AMONG CLINICIANS: Awareness of spasticity across the medical specialties.

Clinical Capacity and Capabilities: Please rank the following based upon your knowledge and experience, which areas must be addressed by U.S. healthcare to address the clinical capacity and capabilities challenges for spasticity. Please rank them from most important (1) to least important (7).

#1: EDUCATE CLINICIANS REGARDING PATIENT NEEDS: Increase access to clinician education on how to assess and treat those with spasticity about the needs of those with spasticity (i.e., how to treat and manage cases in an outpatient vs. institutional setting).

Weighted Average: 11.7

Rank	1	2	3	4	5	6
# of Responses	9	8	5	1	4	1

#2: IMPROVE DIAGNOSIS: Improve the diagnosis of spasticity in those with stroke, TBI, and SCI.

Weighted Average: 14.5

Rank	1	2	3	4	5	6
# of Responses	8	4	3	7	2	4

#3: ENSURE ENVIRONMENT OF INCENTIVES: Ensure a favorable regulatory and business environment that incentivizes providers.

Weighted Average: 17.3

Rank	1	2	3	4	5	6
# of Responses	5	7	3	2	4	8

#4: INCREASE CASE FOLLOW-UP INCIDENCE: Increase the incidence of spasticity case follow-up by appropriate providers.

Weighted Average: 17.3

Rank	1	2	3	4	5	6
# of Responses	5	2	3	7	8	4

#5: IMPROVE TREATMENT OPTIONS: Improve the implementation of interventional treatment options (i.e., botulinum toxin injections, intrathecal baclofen pumps) in clinical workflows.

Weighted Average: 18.3

Rank	1	2	3	4	5	6
# of Responses	0	4	9	7	1	6

#6: CLARIFY PROFESSIONALS' ROLES: Clarify the roles and challenges of various health professionals in expanding care for those with spasticity.

Weighted Average: 19.3

Rank	1	2	3	4	5	6
# of Responses	0	5	5	4	9	5

#7: Other: Write-In Responses:

- ARTICULATE STANDARD OF CARE: Protocol spasticity treatment guidelines published by national organizations for clinicians to become standard of care.

- IMPROVE INCENTIVES FOR PROVIDERS: Industry can train physicians, but there needs to be incentives for these providers to want to be in this space. Need to make sure that spasticity management is a field that providers want to enter.

- REDUCE TIERED APPROACH: Reduce the perception that spasticity treatment should be provided in a tiered approach.

- INCREASE COORDINATION BETWEEN PROVIDERS: Coordination between providers for comprehensive care.

Mr. Diefenbach invited the attendees to introduce themselves and called attendees alphabetically (see below Summit Attendee Introductions and Breakout Room Assignments). Next, Mr. Diefenbach introduced the video presentation from Alberto Esquenazi, MD, FAAPMR (see below Video Presentation) and concluded by introducing Drs. Kwasnica and Patel.

Summit Attendee Introductions and Breakout Room Assignments

The Summit attendees were asked to introduce themselves and share their name, affiliation with their current organization and position and longevity in the field. They were also asked to identify and share the survey result that was unexpected or of personal interest. Responses from attendees, organized by breakout sessions groups, regarding longevity in the field of spasticity and survey/barrier interests are as follows:

ACCESS TO CARE:

John Baratta, MD, MBA, FAAPMR
Seven years; Appropriate identification of spasticity, diagnosis

Sonja Boone, MD, FACP
Five-and-half years; Incentivize and educate primary care physicians to diagnose spasticity

Joseph Burris, MD, FAAPMR
Since residency; Access to care, from rural areas to areas for expert care

Eric Nelson
23 years; Appropriate referral to a specialist by primary care physicians

Kevin O'Brien
30 years; Awareness, incentives for doctors

Linda Page
25 years; Standards and incentives for clinicians to provide care

Divya Singhal, MD, FAAN
Since residency; Access and transportation, technological access, clinical flow: logistics from diagnosis to treatment

Monica Verduzco-Gutierrez, MD, FAAPMR
Access to care, Documenting access challenges, treatment for underserved (Medicare/Medicaid)

Christopher Watters
Appropriate model for standard of care

PATIENT AND CAREGIVER SUPPORT:

Susan Connors
17 years; Patient education about what can be treated, Medicare reimbursement

Monica de Abadal, MD
20 years; Team approach (inaudible)

Steve Gnatz, MD, MHA, FAAPMR
40 years; Consolidated billing, high cost of materials

Michael Hast, PhD
Seven years; Awareness and education

Kimberly Heckert, MD, FAAPMR
Education of spasticity experts, incentives to treat spasticity

Helen Hoenig, MD
Geriatrics and rehabilitation, complications can affect care

Mariana Nelson, PhD
Nine years; Standard of care, treatment guidelines

Anna Taylor
Four-and-half years; Patient and caregiver awareness

CLINICAL CAPACITY AND CAPABILITIES:

Jennifer Crocker, MD, FAAPMR
20 years; Access to care

Matt Cross, PhD
One year: Patient and caregiver awareness

Steven Flanagan, MD, FAAPMR, AAPM&R President
30 years; Increase awareness of spasticity among primary care physicians and providers

Richard Harvey, MD, FAAPMR
30 years; Access to care, transport services especially since COVID

Chip Mitros
18 years; Access to care

Jose Naranjo
Eight months; Awareness and documenting the issue

Samantha Olds Frey
Nine years; Underserved population and removing barriers

Richard Shields, PT, PhD, FAPTA
20 years; Differential diagnosis of spasticity and developing standards

Alex Vosooney, MD
Help patients understand care plans

NOT ASSIGNED TO ROOM:

Alfred Gellhorn, MD
Education and incentives

Christina Kwasnica, MD, FAAPMR
Standards of care

Atul Patel, MD, MHSA, FAAPMR, AAPM&R Treasurer
Access to care, intrigued by tiered approach

Video Presentation

Greetings were sent from Alberto Esquenazi, MD, FAAPMR who was unable to attend the Summit. (*PM&R, Thomas Jefferson University Hospital, Moss Rehab Physical Medicine Associates.)*

Current State of Spasticity: Presentation and Discussion

Dr. Christina Kwasnica, Spasticity Summit Co-Chair, started the presentation “Current State of Spasticity in the United States: Access to Care, Patient and Caregiver Support, and Clinical Capacity and Capabilities.” Dr. Kwasnica began by describing the physical and mental effects of spasticity. Dr. Kwasnica explained her experience treating stroke and brain injury patients to be highly focused on improving patients’ weaknesses. With the recovery of strength, patients will often develop abnormal motor patterns, which are spasticity. Although there is initially a period of time where spasticity can help movement, typically, individuals with spasticity often have discomfort, difficulties with daily activities and other medical complications. Spasticity is also challenging to caregivers, and providers have the opportunity to help make a significant difference in patients’ and caregivers’ lives.

Dr. Kwasnica further elaborated that nearly 800,000 people each year will have a stroke, and between 25% and 43% of people will develop spasticity in their first post-stroke year. In addition, spasticity affects people with cerebral palsy, multiple sclerosis, traumatic brain injury, spinal cord injury and stroke survivors. Some populations, such as COVID-19 patients and Hispanic and Black individuals, have an increased risk of strokes. In addition, certain states in the U.S. have higher stroke rates compared to other states, possibly due to diet, lifestyle, socioeconomic status and healthcare facility quality. These states are often rural, and these geographic areas may lack physiatric services making the challenge of access to care significant.

Dr. Kwasnica presented socioeconomic factors which impact spasticity and reviewed the IDAHO Criteria for optimal management of spasticity:

- Infrastructure (Full-time emotional and physical support gives people with spasticity an advantage)
- Desire (patients’ interest in pursuing treatment goals, along with realistic goals, may improve progress, teamwork between patient and provider)
- Ability (cognitive impairment and lesser degrees of motor control hinder recovery)

- Hospital access (people who live closer to professional care services have better access to care, insurance coverage barriers)
- Opportunity (people with better financial resources and insurance have better access to care).

Dr. Kwasnica commented on the chronic care of patients and the relationships established between patients and providers. Unfortunately, many providers cannot provide all treatments, especially neurotoxin treatments. Barriers and questions regarding getting the proper treatment to the right patient at the right time, insurance coverage of treatments, and transportation difficulties interfering with treatment schedules often discourage providers from treating spasticity patients.

Dr. Kwasnica further discussed cost and reimbursement of neurotoxin treatment and intrathecal baclofen pump management, highlighting the challenge of growing the field of spasticity care. Training providers on how to perform injections is essential for quality medical care. However, training providers on running a successful spasticity practice is also critical for ensuring that enough providers are available to treat spasticity patients. Dr. Kwasnica then pivoted to highlight difficulties in spasticity diagnosis. Spasticity can be overlooked in stroke, spinal cord injury and traumatic brain injury because of other more urgent medical issues. Often home caregivers may not recognize the condition, and the onset of spasticity can be months after the initial injury. Patients with spasticity can be undertreated due to a lack of access to clinics, delayed diagnosis and care, delayed referral to specialists, suboptimal treatment options where providers do not offer all available treatments, and financial barriers to insurance and treatment cost.

Building upon Dr. Kwasnica’s presentation, Atul Patel, MD, MHSA, FAAPMR, Spasticity Summit Co-Chair, continued the discussion on spasticity by pointing out that even in wealthy communities, lack of awareness and challenges of access to care are significant. Barriers to treatment are not exclusive to rural areas. Dr. Patel began his presentation on the topic of stroke as the number one cause of disability because 50% of people who have had a stroke are still alive after five years. The risk factors for stroke are the same as heart disease: hypertension and diabetes. Within the U.S., people are developing these conditions at a younger age. Further, as the U.S. population is predicted to have 83.7 million Americans aged 65 years or older by 2050, spasticity is expected to increase due to stroke and spinal cord and traumatic brain injuries due to falls. Two-thirds of people who have had a stroke are over the age of 65, and as the population ages, the number of individuals with spasticity is expected to rise.

Dr. Patel elaborated on the difficult and stressful role of spasticity caregivers who are often required to perform complex medical tasks. Most caregivers are women, and more women end up in nursing homes than men, especially with incontinence. Often caregivers are unable to work while caring for loved ones with spasticity. Providing care to spasticity patients can significantly negatively impact the emotional, financial and social well-being of informal caregivers. Dr. Patel explained that spasticity can be a complication of stroke, and concomitantly, spasticity as a condition has complications including hygiene and mobility challenges.

Dr. Patel then provided an overview of the types of healthcare providers that treat spasticity, including primary care physicians, neurologists, neurosurgeons, orthopedic surgeons, physiatrists, occupational therapists, physical therapists and speech pathologists. Often specialists do not receive training in spasticity, yet they are the individuals making the referrals. Spasticity is a complex problem that requires a comprehensive treatment plan.

Dr. Patel outlined the types of conservative treatments, including avoidance of noxious stimuli, direct tendon pressure, stretching, and physical and occupational therapy. Dr. Patel noted that simple changes or corrections, such as removing an ingrown toenail, soothing an insect bite, minimizing noxious stimuli or applying ice/heat, can significantly improve tone and reduce spasticity. He also summarized commonly used oral medications, such as baclofen, clonidine, tizanidine, benzodiazepines, gabapentin and dantrolene sodium. The common complication with medication use is side effects; no single treatment is perfect.

Dr. Patel reviewed interventional therapies such as intrathecal baclofen and botulinum neurotoxin. Intrathecal baclofen is delivered directly into the spine and has good results for lower limb spasticity but is not as effective for upper limb spasticity. Proper patient selection, device placement, and reimbursement are all barriers to the use of intrathecal baclofen. Dr. Patel concluded his presentation by discussing industry. Data collected to determine the number of patients who are being treated for spasticity showed that less than 5% of patients who would benefit from neurotoxin treatment receive treatment. In addition, less than 1% of patients who would benefit from intrathecal baclofen receive this treatment. More than 80% of people who should be treated for spasticity are not getting treatment. Dr. Patel summarized that spasticity is a complex problem, and a significant barrier is getting more providers to care for spasticity patients. It is essential to develop a plan to reduce the cost of treatment and provide better care; collectively, the group today should come together to develop a plan to improve treatment over the next few years.

Mr. Diefenbach continued the conversation by asking the attendees if they had comments or questions regarding the presentation. Comments from attendees were as follows:

- The logistics of getting patients from a nursing home to the site for care while fearing their baclofen pump will be depleted is a common barrier for patients. It is not always an issue of finances or access to quality care.

- Dr. Richard Harvey explained the tiered care/pyramid structure of care, which has the bottom level representing treatments such as stretching and physical therapy, the middle level representing oral medications, and the top-level representing surgery. Pyramid or tiered care is not always practical, from a clinician's opinion, but insurance companies often require healthcare providers to work up the pyramid. Clinicians should be able to decide the best approach for patient care instead of an insurance company mandate to work up a tiered care pyramid. Clinicians could be tiered theoretically, with lower-level clinicians to work on more straightforward patient issues and specialized clinicians to work on more complex care issues.

- Professional relationships are powerful tools to improve care, and the potential for partnership among all providers is essential.
- Encouragement of residents to focus on spasticity as a specialty instead of pain management: "Spasticity treatments work," while pain treatments don't often work.
- Physicians should be incentivized to do the challenging work of spasticity care and bringing patients to their facility.
- Policies that help institutions recruit physicians to care for patients should be implemented.

Mr. Diefenbach reiterated the detailed instructions for breakout groups and the session was concluded.

Priorities and Consensus: Breakout Session #1

Access to Care Breakout Reporter Summary:

The group consensus was that the top priority should be the documentation of the access challenge, the second-ranking priority was articulating the guidelines for standards of care, the third priority was to ensure a favorable regulatory and business environment, and the fourth priority was to increase the number of providers.

First, the scope and scale of the problem need to be demonstrated. Secondly, it is vital to improve the problem. Thirdly, having more providers for spasticity and healthcare in general is critical.

Documentation is required, not only for stroke but to encompass all motor neuron injuries. It is important to demonstrate the urgency and have strong evidence, maybe through existing databases. There are existing standards of care, but they are not necessarily focused on outcomes, such as functionality.

To ensure a favorable business environment, RUC advocacy is essential to improve reimbursement for complex spasticity management. Discussions with specific insurance plans could facilitate a cost/savings review and demonstrate cost savings by providing proper treatment.

Increasing providers is critical because providers' schedules are at maximum capacity for many months, and patients often wait for care. In addition, advanced practice providers can take on more stable positions to treat spasticity which will help alleviate the burden of specialists. Also, spasticity fellowship programs and resident training education regarding a profitable spasticity practice would be of great value.

#1: Document the extent and impact of the access challenge.

- ✓ Stronger evidence would improve access
- ✓ Broaden the diagnosis beyond just stroke; encompass all upper motor neuron (UMN) injuries
- ✓ Problem is getting bigger with time–evidence should demonstrate urgency
- ✓ Possibly harness existing databases/patient registries to provide evidence

#2: Guidelines for standard of care

- ✓ Articulate the care standards to improve care quality
- ✓ Need to increase the focus on outcomes (e.g., functionality) and good outcome measures

#3: Ensure a favorable regulatory and business/industry environment that incentivizes all stakeholders (e.g., providers, payers, etc.) to help increase care access.

- ✓ Ensure an environment of incentives
- ✓ RVS Update Committee (RUC) advocacy to increase reimbursement for complex spasticity management, especially with intrathecal baclofen therapy (ITB)
- ✓ Insurance plans would perform cost/savings analysis demonstrating lowered overall cost of care with ITB

Additional #4: Increase providers that treat spasticity (e.g., physiatrists, neurologists, advanced practice providers) and increase training programs on how to run spasticity practice.

Patient and Caregiver Support Breakout Reporter Summary:

The group consensus was that the improvement of caregivers and community awareness of spasticity and treatments for empowerment was most important. There will be no treatment if there is no awareness of the problem. In addition, it will be impossible to identify who these patients are and where they are without awareness. Increased awareness can be accomplished by providing high-quality materials to patients and families about available treatments.

There is a need for support and resources for caregivers, aid in addition to monetary support. Also, there is a need for advocacy and support from the community. For example, an individual in church viewed a commercial about spasticity and was able to educate another individual and empower someone to seek treatment. If we have no awareness, we have no hope.

There is a need to increase the ability of spasticity patients, regardless of race or ethnicity, to follow their treatment care plan. We can accomplish this through financial support, caregiver training, home healthcare training and better transportation. Also, it is essential to provide greater access, such as ramps, transportation or more aids. Unfortunately, there is a substantial shortage of nurses and aids. Also, there is a need to optimize the mental health of people with spasticity and their caregivers. Caregiver burnout is an important issue.

#1: Improve caregiver and community awareness of spasticity and spasticity treatments for the purpose of patient/caregiver empowerment.

- ✓ Develop high-quality patient/caregiver educational materials about spasticity and available treatments
- ✓ Improve support for untrained patients/caregivers (financial and beyond)
- ✓ Equip patients/caregivers for advocacy (community, church, social groups empowering individuals)

#2: Increase ability for people with spasticity to follow their care plan across all racial and ethnic groups, including those individuals who are cognitively impaired.

- ✓ Provide financial support (insurance coverage) for respite care, caregiver support and home healthcare training, and transportation
- ✓ Provide greater access to physical support (ramps, transportation, patient aids and nurses)
- ✓ Optimize mental and emotional health for people with spasticity and caregivers

Clinical Capacity and Capabilities Breakout Reporter Summary:

The group consensus was that access was a critical issue and not every geography is similar to “downtown Chicago.” There is a need to provide a set of standards that guides clinicians with enough flexibility to allow the development of a Center of Excellence, regardless of what is available to them, as long as the healthcare providers route the patient to appropriate care. Importantly, stakeholders should be involved in this process.

Treatment guidelines should be published and available. It is unclear whether there is information available to create a robust set of standards that insurers would accept. Often there needs to be a more streamlined approach to care so that patients are referred to specialists appropriately. There is a need to clarify goals and challenges; sometimes challenges are common and sometimes unique and may depend on geography.

Incentives are often financial but are not always monetary. Spasticity management is a lifestyle choice, especially in small communities, and there is a need for support and infrastructure to encourage more providers. A quarter of physiatrists treat movement disorders and spasticity, and that number needs to increase.

#1: Increase access to clinician education on how to assess and treat those with spasticity about the needs of those with spasticity (i.e., how to treat and manage cases in an outpatient vs. institutional setting).

- ✓ Educate clinicians regarding patient needs
- ✓ Stratified Center of Excellence (CoE): not every community/geography can offer the same treatments; need conceptual markers
- ✓ Need standards that provide guidance but allow flexibility for providers to be a CoE that routes patient to appropriate care, regardless of geography or resources
- ✓ Multiple disciplines and stakeholders are involved in this process

#2: Protocol spasticity treatment guidelines published by national organization for clinicians to become standard of care.

- ✓ Automatic specialty follow-up
- ✓ Tiered approach when useful
- ✓ Clarify roles and challenges (challenges may be common or unique and sometimes related to geography)
- ✓ Include advanced treatments (Tx)

#3: Incentive for providers to want to be in this space. Need to make sure that spasticity management is a field that providers want to enter.

- ✓ Financial incentives
- ✓ Improved quality of lifestyle incentives for providers (beyond financial incentives)
- ✓ Favorable regulatory and business environments
- ✓ Greater financial resources
- ✓ Workforce issues: 12,000 PM&R physicians but only 25% of those treat spasticity and movement disorders

Dr. Kwasinca emphasized that there was great synergy among the groups. Transportation as a barrier was a common theme in many groups. Also, workforce issues were a commonly discussed topic among the groups. Dr. Kwasnica expressed there is a need to focus on how to change the future of medicine. Building a workforce is critical. Caregiver training was an important issue among the groups, and there is a need to pull resources together to help caregivers provide more care and help patients access care.

Dr. Patel encouraged attendees to continue to share ideas. He observed common themes, such as the need for documentation, data and research to present to industry and payer representatives. Dr. Patel mentioned that cost is an outcome as important as function. Treatments should cost less or save money; once that is optimized, patient care will improve. There is a need to be flexible; there will not be one standard solution to a problem. Different geographic locations will require different solutions.

An attendee noted that spasticity is a global problem and incorporating the voice of patients and caregivers is essential to solving barriers to treatment.

Priorities and Consensus: Breakout Session #2

Access to Care Breakout Reporter Summary:

It is crucial to demonstrate that the overall cost of healthcare will be lowered with appropriate spasticity treatment. There is a need for evidence to communicate this concept to providers and healthcare payers. Options discussed within the group included partnering with payers to identify patients who would benefit from treatment; often, payers reach out to providers with payer suggestions for treatment. Collaboration with bundled care payment structures or ACOs to identify and educate on the need for spasticity management to lower costs by reducing hospital readmissions and secondary complications would be valuable. Partnering with the stroke association and brain association could also help achieve the goal.

There is a need to improve the articulation of care standards for spasticity and have an established dissemination plan for those standards for providers in PM&R and others. In addition, it would be useful to have an educational outreach program for providers.

Working with RUC to improve reimbursement could be achieved by partnering with clinicians who do similar work, such as pain management and neurology.

Increasing the workforce will improve access to care by increasing providers of spasticity. This can be accomplished by educating residents on how to operate a profitable spasticity practice. Also, advanced practice providers could offer spasticity treatments. Training programs for students and unmatched residency candidates that could be involved in apprenticeships will also contribute to growing the workforce.

Improving coding for spasticity diagnosis through webinars and podcasts and partnering with industry to increase education for providers are also valuable solutions to access to care barriers.

#1: Demonstrate with evidence that overall cost of healthcare can be lowered with appropriate spasticity treatment.

- ✓ Partner with payers to identify patients who could benefit from treatment (care suggestions)
- ✓ Accountable Care Organizations (ACO)
- ✓ Bundled care payment structure
- ✓ American Stroke Association (ASA), Brain Injury Association (BIA)
- ✓ Patient registries

#2: Improve articulation of care standards (Academy white paper).

- ✓ Establish dissemination plan of standards for PM&R and other providers
- ✓ Educational outreach to other specialties; partner with American College of Physicians (e.g., presentations, podcasts on optimal approach for spasticity management)
- ✓ Create handout for patients/families

#3: Improve reimbursement for spasticity management.
  - ✓ Discuss with AAPM&R Reimbursement Committee
  - ✓ Work with RUC to discuss modifying reimbursement (especially for ITB therapy)
  - ✓ Partner with other related specialties (pain management, neurology)

<u>Patient and Caregiver Support Breakout Reporter Summary:</u>

The consensus and primary goal of this group was awareness. Without awareness, patients will not seek treatment. There is a need to identify what resources are available. This assessment will require funding and support. Master of Public Health Students can assist the Academy with this assessment. The students could produce a capstone paper as a result of their research. The students would search for existing informational and educational resources, looking across broad areas for this information. The goal is to connect patients and caregivers to this information. Also, using celebrities or influencers to increase awareness could be helpful. It was suggested to see how other disease state organizations raise awareness and disseminate education.

There is a need to identify and organize a “home base” for spasticity, such as the website spasticity.org. The spasticity coalition will be dedicated to the creation and oversight of the home base website spasticity.org. The coalition will identify and prioritize the gaps and needs for spasticity treatment. There is a critical need for representation from patients and caregivers, possibly through a survey. Understanding what information sources patients trust and do not trust would be valuable for the spasticity coalition. The website would be linked to multiple channels, other organizations and electronic medical records, allowing patients to understand available treatments and where to find care.

Identifying a task force of experts to contribute to the coalition would be valuable, providing expertise and knowledge. In addition, the coalition could develop “tool kits” for patients as a guide about insurance coverage and how to manage the emotional demands of spasticity and treatment availability. “Living Well With Spasticity” is a phrase and concept that will help patients chronically manage spasticity. A robust marketing campaign through social media would also increase awareness.

#1: Assessment of currently available resources (informational resources, educational, e.g., stroke.org/spasticity)
  - ✓ Use students in Master of Public Health (MPH) programs or volunteers
  - ✓ Find existing informational and educational resources from web, print, social media or influencers in order to connect caregivers and patients to this
  - ✓ Look at how other disease state organizations educate and disseminate information (e.g., Parkinson’s)

#2: Identify and organize a “home base” for spasticity
  - ✓ Develop website spasticity.org

- ✓ Form spasticity coalition for visibility
- ✓ Coalition will identify gaps and needs and prioritize (barriers of transport, financial, etc.)
- ✓ Need representation from patients and caregivers (survey patients about how they find information and what information sources they trust)

#3: Create spasticity coalition (“home base”) website linked to multiple channels/other organizational websites.

- ✓ Epic/Electronic Medical Records (EMR)/Up to Date
- ✓ Traumatic Brain Injury (TBI) websites (TBI.org)
- ✓ American Stroke Association/American Heart Association (ASA/AHA)
- ✓ Pharmaceutical and device company websites
- ✓ National Council on Ageing, American Geriatric Society
- ✓ American Medical Association (AMA)
- ✓ “Others” National Caregivers Association

#4: Education

- ✓ Create task force of experts (post-assessment)
- ✓ Create spasticity coalition
- ✓ Create tool kit for helping patients/caregivers navigate their condition and care (survey patients to help identify barriers, capture “Living Well With Spasticity” to help understand insurance coverage and chronically managing spasticity, include emotional health education)
- ✓ Marketing campaign (social media, TV, print)

Clinical Capacity and Capabilities Breakout Reporter Summary:

Developing a white paper, a consensus statement, will bring together not only PM&R but all stakeholders. Consensus statements can be developed through video chats with various experts to generate a white paper. There is a need to identify the key stakeholders, such as physical therapists, occupational therapists, primary care physicians, etc. All stakeholders should participate in the discussion.

Evidence generation is needed for consensus statements and can be achieved through a task force. Aggregation of data is critical to combine all stakeholder’s information needed by the organization. PM&R champions to increase local awareness would be helpful toward the cause of improving spasticity care. Working with primary care physicians and stakeholders will create a win-win scenario, helping improve the quality-of-life of providers in addition to financial incentives.

There is a need for the creation of a “Center of Excellence” program, not just for major institutions but aligning multiple centers in an area. For example, hosting quarterly webinars to share best practices and use that opportunity to highlight providers in the area would be helpful. Sharing successes through this venue would be of value.

#1: Develop, publish and disseminate a white paper/consensus guidance statement.
- ✓ Statement bringing together multiple stakeholders on the diagnosis/management of spasticity (consensus statements developed through video chats of experts sharing opinions)
- ✓ Work with family practice physicians, speech therapists, physical therapists, occupational therapists, and other key stakeholders so all opinions are represented.

#2: Create an evidence generation plan aggregating data across all spasticity organizations for consensus with a systematic review of the data gathered.

#3: Mobilize local PM&R champions (physiatrists, local organizations) to address and advance issues in spasticity in local institutions and communities.

#4: Improve continuation of care by working with primary care physicians and other stakeholders to create win-win workflows for patients with spasticity.

#5: Create a "Center of Excellence" program to recognize providers of spasticity care.
- ✓ Combine multiple centers in an area to create CoE
- ✓ Create webinars to share best practices

Priorities and Consensus: Full Group Discussion

Solutions identified from Breakout Session #2 were prioritized by attendees placing a dot or star on the specific idea presented when in agreement with the solution. The color of dot or star was based on attendee affiliation: pink representing clinicians and healthcare providers, orange representing patient advocates, and green representing industry and payer representatives. Priorities and consensus from Breakout Session #2 showed that the majority of attendees in each group agreed the top five to seven solutions to address barriers for the three key areas are as follows:

Access to Care:

#1: Demonstrate with evidence that overall cost of healthcare can be lowered with appropriate spasticity treatment.
- ✓ Partner with payers to identify patients who could benefit from treatment (care suggestions) (1 pink dot PM&R)
- ✓ Accountable Care Organizations (ACO)
- ✓ Bundled care payment structure
- ✓ American Stroke Association (ASA), Brain Injury Association (BIA)
- ✓ Patient registries

TOTAL:
11 dots, 1 star: Clinicians and Healthcare Providers (7 dots and 1 star PM&R)
6 dots: Industry and Payer Representatives

#2: Improve articulation of care standards (Academy white paper).

- ✓ Establish dissemination plan of standards for PM&R and other providers
- ✓ Educational outreach to other specialties; partner with American College of Physicians (e.g., presentations, podcasts on optimal approach for spasticity management) (1 pink dot PM&R)
- ✓ Create handout for patients/families (1 green dot)

TOTAL:
6 dots: Clinicians and Healthcare Providers (5 dots PM&R)
9 dots, 1 star: Industry and Payer Representatives

#3: Improve reimbursement for spasticity management.

- ✓ Discuss with AAPM&R Reimbursement Committee
- ✓ Work with RUC to discuss modifying reimbursement (especially for ITB therapy) (1 pink dot and 1 pink dot PM&R)
- ✓ Partner with other related specialties (pain management, neurology) (1 pink dot)

TOTAL:
8 dots: Clinicians and Healthcare Providers (5 dots PM&R)
2 dots: Patient Advocates
6 dots, 1 star: Industry and Payer Representatives

#4: Increase providers who can offer spasticity management/increase workforce.

- ✓ Incorporation of education on how to operate a profitable spasticity management program (residency, fellowship) (1 pink dot PM&R, 2 green dot)
- ✓ Advanced Practice Providers under physiatrist/neurologist supervision
- ✓ Training programs for medical students and unmatched residency applicants (apprenticeship programs)

TOTAL:
9 dots: Clinicians and Healthcare Providers (8 dots PM&R)
2 dots: Patient Advocates
11 dots: Industry and Payer Representatives

#5: Improve coding and referral practices for spasticity-related diagnoses.

- ✓ Webinars and podcasts for providers

- ✓ Cascade education through other medical societies
- ✓ Partner with industry to offer education to providers and referral sources

TOTAL:
4 dots, 1 star: Clinicians and Healthcare Providers (3 dots PM&R)
2 dots: Patient Advocates
1 dot: Industry and Payer Representatives

Patient and Caregiver Support:

#1: Assessment of currently available resources (informational resources, educational, e.g., stroke.org/spasticity)

- ✓ Use students in Master of Public Health (MPH) programs or volunteers
- ✓ Find existing informational and educational resources from web, print, social media, or influencers in order to connect caregivers and patients to this information (7 pink dots, 2 orange dots, 3 green dots)
- ✓ Look at how other disease state organizations educate and disseminate information (e.g., Parkinson's) (1 pink dot, 1 pink dot PM&R, 2 green dots)

TOTAL:
9 dots: Clinicians and Healthcare Providers (5 dots PM&R)
2 dots: Patient Advocates
5 dots: Industry and Payer Representatives

#2: Identify and organize a "home base" for spasticity

- ✓ Develop website spasticity.org (1 green)
- ✓ Form spasticity coalition for visibility (1 pink dot, 3 pink dots PM&R, 1 pink star, 3 pink stars PM&R; 2 orange stars; 4 green dots, 2 green stars)
- ✓ Coalition will identify gaps and needs and prioritize (barriers of transport, financial, etc.) (2 pink dots PM&R)
- ✓ Need representation from patients and caregivers (survey patients about how they find information and what information sources they trust)

TOTAL:
6 dots, 4 stars: Clinicians and Healthcare Providers (5 dots, 3 stars PM&R)
2 dots, 2 stars: Patient Advocates
5 dots, 2 stars: Industry and Payer Representatives

#3: Create spasticity coalition ("home base") website linked to multiple channels/other organizational websites.

- ✓ Epic/Electronic Medical Records (EMR)/Up to Date (1 pink dot)

- ✓ Traumatic Brain Injury (TBI) websites (TBI.org)
- ✓ American Stroke Association/American Heart Association (ASA/AHA) (1 pink dot)
- ✓ Pharmaceutical and device company websites
- ✓ National Council on Ageing, American Geriatric Society
- ✓ American Medical Association (AMA) (1 green dot)
- ✓ "Others" National Caregivers Association

TOTAL:
6 dots, 2 stars: Clinicians and Healthcare Providers (3 dots, 2 stars PM&R)
7 dots, 1 star: Industry and Payer Representatives

#4: Education

- ✓ Create task force of experts (post-assessment)
- ✓ Create spasticity coalition (3 green dots)
- ✓ Create "tool kit" for helping patients/caregivers navigate their condition and care (survey patients to help identify barriers, capture "*Living Well With Spasticity*" to help understand insurance coverage and chronically managing spasticity, include emotional health education) (6 pink dots, 5 pink dots PM&R, 10 green dots)
- ✓ Marketing campaign (social media, TV, print) (1 pink dot PM&R, 1 green dot)

TOTAL:
12 dots: Clinicians and Healthcare Providers (6 dots PM&R)
2 dots: Patient Advocates
17 dots: Industry and Payer Representatives

Clinical Capacity and Capabilities:

#1: Develop, publish and disseminate a white paper/consensus guidance statement.

- ✓ Statement bringing together multiple stakeholders on the diagnosis/management of spasticity (consensus statements developed through video chats of experts sharing opinions)
- ✓ Work with family practice physicians, speech therapists, physical therapists, occupational therapists, and other key stakeholders so all opinions are represented.

TOTAL:
9 dots, 5 stars: Clinicians and Healthcare Providers (8 dots, 2 stars PM&R)
2 dots: Patient Advocates
7 dots, 6 stars: Industry and Payer Representatives

#2: Create an evidence generation plan aggregating data across all spasticity organizations for consensus with a systematic review of the data gathered.

TOTAL:
8 dots: Clinicians and Healthcare Providers (5 dots PM&R)
2 dots: Patient Advocates
10 dots: Industry and Payer Representatives

#3: Mobilize local PM&R champions (physiatrists, local organizations) to address and advance issues in spasticity in local institutions and communities.

TOTAL:
2 dots: Clinicians and Healthcare Providers (2 dots PM&R)
2 dots: Industry and Payer Representatives

#4: Improve continuation of care by working with primary care physicians and other stakeholders to create win-win workflows for patients with spasticity.

TOTAL:
14 dots: Clinicians and Healthcare Providers (9 dots PM&R)
2 dots: Patient Advocates
5 dots, 1 star: Industry and Payer Representatives

#5: Create a "Center of Excellence" program to recognize providers of spasticity care.
- ✓ Combine multiple centers in an area to create CoE
- ✓ Create webinars to share best practices

TOTAL:
5 dots, 1 star: Clinicians and Healthcare Providers (5 dots, 1 star PM&R)
5 dots: Industry and Payer Representatives

Discussion Highlights

The majority of attendees agreed that the high-priority solutions to barriers for spasticity care included:
- Developing a guidance/consensus statement
- Developing a tool kit to help navigate chronic spasticity care
- Developing a spasticity coalition
- Access to care is an important key area for all attendees

> *“Our primary goal is awareness. Without awareness, patients will not seek treatment… If there is no awareness of the problem, there will be no treatment. We will never know who these patients are and where they are.”*
>
> **Kimberly Heckert, MD, FAAPMR**

Discussion Summary

Mr. Diefenbach engaged the audience by starting a discussion about the voting results. Mr. Diefenbach invited the attendees to notice and comment on trends in the voting results. He noted that many of the representatives from the Patient Advocate group had to leave the Summit early so their votes would be underrepresented.

Meaningful results from the voting showed that Access to Care was a vital key area among all attendees. Also, the idea to develop, publish and disseminate a white paper/consensus guidance statement under Clinical Capacity and Capabilities had many star votes as a high-ranking solution. Creating a tool kit for “*Living Well With Spasticity”* and forming a spasticity coalition under Patient and Caregiver support was also highly ranked, especially by industry and payer representatives.

Mobilizing local PM&R champions did not rank as a high-priority solution, possibly because other priorities were more critical or because most providers need more time to dedicate to this cause. However, the assessment of available resources to provide patients under Patient and Caregiver Support was discussed to be an actionable solution that could be enacted immediately to affect change. Looking at the American Stroke Association (ASA), as an example, was suggested to be a guide for organizing and disseminating educational information.

The most challenging solution was proposed to be the development of standard of care guidelines extended to include outcomes measurement tools because clinical trials and industry-sponsored studies require time to collect data and validate the results. In addition, results from evidence-based research studies need to be repeatable and with minimal bias. It was discussed that studies are time-consuming but often do not result in policy changes for insurance coverage and Medicare reimbursement.

Mr. Diefenbach provided an overview of the day by sharing a summary slide presentation. Mr. Diefenbach began by emphasizing an urgency to solve the barriers to spasticity care. Nothing begins, and nothing happens without urgency. The challenges are significant. The scope of this topic will only increase as the population ages. There is a need to document the inequality of access to care driven by geography and clinician shortage. Proof of what needs to be done is required. In addition, there is a need to increase the number of available experts to provide the care (e.g., advanced practice providers, incent providers). To encourage clinicians to provide services, standards of care need to be articulated. Once the best practice is defined, we can identify gaps in care. There is a need to complete research and gather data to provide proof of the depth of the problems in order to justify a change. Education of patients and caregivers and their partnership is essential to improve care for spasticity patients. Mr. Diefenbach stated that we need to add their voices to ours to create change. This partnership will help patients to follow their care plan and increase their quality of life. Payers need to be aware that if patients are treated promptly and providers have better reimbursement, there will be cost savings and incentivize providers to treat spasticity. Mr. Diefenbach elaborated that layered teams need to be organized to relieve the burden on spasticity providers and encourage more providers to treat spasticity. As clinical capacity expands, providers will be better able to meet the growing needs of spasticity patients.

Important points from Mr. Diefenbach's summary are as follows:

- Change is urgent and the challenge is significant
- Document inequality of access
- Grow available expertise
- Articulate standards of care/best practices
- Gather data to identify gaps
- Educate patients and caregivers
- Make patients better partners in care
- Increase awareness of payers
- When payers change policy, providers will be incentivized
- Build layered teams to solve barriers
- Expand clinical capacity to better meet the growing needs of patients

Reflections and Next Steps

Dr. Kwasnica reinforced how it was encouraging to observe the groups from all representations. She was pleased to watch people talking, listening and producing ideas together. Dr. Kwasnica noted it was a significant number of people working together without the groups being too large to be productive. She proposed that for future meetings, if there are groups that were not represented at the Summit that attendees would like to see at the next meeting, please add that detail to the survey. Spasticity care is a complex problem that needs an open discussion area, and we would like to increase the number of people participating. There will be progress made from the Summit today.

Dr. Patel commented that this was the first step and that the Summit has momentum. However, spasticity is a complex problem to be solved like a jigsaw puzzle. Adding solutions like pieces will require dedication and hard work. Drs. Kwasnica and Patel concluded the discussion by informing the attendees that they would be asked to complete a post-Summit survey and a general survey.

Conclusion and Farewell

Drs. Kwasnica and Patel closed the AAPM&R Spasticity Summit by emphasizing to attendees that the Summit is intended as a springboard for meaningful and ongoing collaborations that can increase the quality-of-life for spasticity patients and caregivers. Drs. Kwasnica and Patel thanked the attendees and participants, as well as AAPM&R, for its efforts and support.

FUTURE PERSPECTIVES

The outcome of the Summit will be a three to five-year plan to tackle the barriers and implement solutions identified, a publication of the consensus-building process, and a commitment to continue conversations and accountability to improve spasticity care.

POST-SUMMIT SURVEY

Results to come.