The core of CNS’ mission is to enhance health and improve lives. We achieve this in large part by developing educational content and courses to help our members stay on top of developments in the field, and to collaborate on clinical research. Just as important though, are CNS’ efforts to advocate on behalf of our members and their patients.

For much of our history, the CNS has worked on your behalf in Washington DC to protect reimbursement and access to care, grow research funding, and ensure quality in neurosurgical training. Drs. Khalessi, Lonser and Babu highlight the critical work the Washington Committee continues to do on behalf of our neurosurgery on page 4, while Katie Orrioco shares an update on our recent work to address prior authorization on page 20.

Drs. Maryam Rahman and Tiffany Hodges share the recent efforts of CNS Equity, Diversity and Inclusion Committee to begin addressing diversity and equity challenges on the CNS Executive Committee, and within our specialty in their article on page 6. Then on page 8, Drs. Nnenna Mbabuike and William Ashley, Jr. take a look at broader disparities throughout the American healthcare system and the critical advocacy efforts needed in neurosurgery to address these inequities.

Perhaps most exciting to me within this issue are the many articles highlighting CNS members and neurosurgical colleagues who have individually and collectively worked to advocate on behalf of patients, ensuring access to care, providing critical health education and improving the health of their communities. Be sure to read their inspiring stories. And for those interested in becoming more involved in health advocacy, Dr. Gaurab Basu shares guidance for recognizing gaps in patient care and outcomes in his article on page 14, as well as strategies to advocate for change.

I hope you enjoy this issue of Congress Quarterly and find it as inspiring as I do. It will be my last issue as editor, after four years at the helm of this publication. I am honored to hand off the reigns to my co-editor, Ellen Air, and my colleague Clemens Schirmer, whom I trust will continue to bring you relevant and engaging articles on topics that are important to your practice and professional development. It has been an honor serving you in this capacity.
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Images in Neurosurgery
For most of us, the COVID-19 pandemic will be the most significant health care event of our professional and personal lives, leaving its mark for decades. By now, you would think we would have considered every possible angle of the pandemic – more than once. But there is one question that continues to resurface in my mind: “What good will come out of this?”

I am confident that when we finally close the book on the pandemic there will be long and informed discussions about lessons learned. But today, I ask you to reflect on what has been the positive impact on our profession given these past 1.5 years?

I have learned several powerful lessons, or perhaps I have relearned them with greater clarity. The pandemic has made me more conscious of the external factors that help or hinder our ability to heal and to deliver positive outcomes. Today, I think more about the:

- Inequities in health care that limit our ability to provide thorough treatment
- Power of community to expedite healthy outcomes – or prevent them
- Support of our legislators to ensure our profession thrives

Although we would all, no doubt, rather spend every working moment on direct patient care, we must view healing more comprehensively.

The first step to serving all of our patients and communities is ensuring our neurosurgery profession is inclusive. That creates a welcoming environment for patients of all backgrounds and will help us identify and overcome obstacles that create inequitable access to health care. The CNS has established an Equity, Diversity and Inclusion Committee to address diversity and equity challenges on the CNS Executive Committee among our members and in our specialty more broadly.

In our field, the CNS has worked to bring together neurosurgeons and neurosurgical team members across geographic boundaries, practice settings and career stages to create opportunities for collaborative learning and growth. After all, inclusion begins at home. The new CNS EDI committee will identify and bring in any groups that have been historically underrepresented. Drs. Maryam Rahman and Tiffany Hodges, co-chairs of the committee, outline some of our early efforts to address these disparities in their article later in this issue.

We must also include policymakers who influence many critical aspects of our practices. The CNS has worked to ensure the support of our legislative branches in Washington DC for more than four decades and has successfully protected reimbursement and access to care, grown research funding and furthered quality in neurosurgical training. You can learn more about that work from Drs. Alex Khalessi, Russ Lonser and Maya Babu, CNS’ appointees to the Washington Committee, in their article on page 4. Katie Orrico, Senior Vice President for Health Policy and Advocacy, also offers an important update on our recent work regarding prior authorization, which I encourage you to read.

As a neurosurgical organization with inclusive coalitions, the CNS has the collective strength of members to impact public policy and the systems that influence patient care and access. But each of us also has the ability to recognize gaps in patient care and outcomes, and take action to address inequities. In this issue, I was pleased to read so many stories about our CNS members working on the
ground to advocate on behalf of their patients and communities. Their passion and commitment inspire me, and they (you) make me proud to be a leader in this organization.

I encourage you to share your needs and concerns with us. Reach out to the Washington Committee as we continue to refine our legislative agenda and our commitment to the health and well-being of our patients and communities. Share your ideas. Advocacy remains an essential part of our member service portfolio, and we are committed to investing in the initiatives that are most critical to your practice and your patients.

This year, as President of CNS in such an unprecedented time, I have learned so many life and professional lessons that I will never forget. It has renewed my commitment to this organization and the work we do. Thank you for your support and your continued commitment. We are making a difference, and we will continue to do so. 🌟
since 1976, the Congress of Neurological Surgeons (CNS) has protected and supported the ability of neurosurgeons to practice while ensuring our patients continued access to appropriate neurosurgical care.

Over the past year, the CNS dedicated more than $1M to support lobbying efforts, policy development, and public relations initiatives through the Joint Washington Committee for Neurological Surgery. The Washington Committee represents a cooperative longstanding partnership between the CNS and the American Association of Neurological Surgeons (AANS). Under the direction of the parent organizations, the Washington Committee monitors government policies impacting neurological surgery and recommends strategic responses. By engaging neurosurgical leadership and subject matter experts, the Washington Office coordinates and develops position statements, formally comments, or takes action on behalf of our specialty.

The Washington Committee is comprised of member and ex-officio member appointees from the CNS and the AANS, as well as liaisons from other neurosurgical organizations such as the joint subspecialty sections. The CNS presently has three member appointees (the authors along with SVP and Washington Office Director Ms. Katie Orrico) and two ex-officio appointees serving on the Washington Committee. We travel to Washington, DC to engage with lawmakers on matters of ongoing importance to the specialty.

Importantly, the Washington Committee further oversees five standing subcommittees — Coding and Reimbursement, Communications and Public Relations, Drugs and Devices, Joint Guidelines Review Committee, and Neurosurgery Quality Council — and neurosurgery’s delegates to the American Medical Association.

Through the work of the Washington Committee, organized neurosurgery has played a central role in a number of health policy achievements, including repealing Medicare’s Independent Payment Advisory Board (which would have mandated steep payment cuts), pushing for medical liability reform, advocating for adequate reimbursement, streamlining quality-improvement initiatives, guaranteeing growing National Institutes of Health funding for neurosurgical research and ensuring the preeminence of quality in neurosurgical education and training. Each year the Washington Committee sets its legislative and regulatory advocacy priorities for the coming year, and earlier this year, the CNS and the AANS released their 2021 legislative and regulatory agenda. The Washington Committee’s staff successfully serve as conveners for coalitions that bridge the House of Medicine and keep neurosurgery’s goals front and center.

In the coming year, organized neurosurgery plans to engage the following issues:

- Protect patients’ timely access to care by reforming utilization review practices, such as prior authorization, step-therapy and Medicare’s appropriate use criteria program for advanced diagnostic imaging;
- Improve the health care delivery system by maintaining existing insurance market reforms and advancing solutions that will lower costs, expand coverage and enhance choice, including establishing network adequacy standards and out-of-network options — with appropriate patient protections for unanticipated medical bills;
- Support quality resident training and education by increasing the number of Medicare-funded residency positions and preserving the ability of surgeons to maximize education and training opportunities within the profession’s current regulatory structures;
- Fix the broken medical liability system by adopting proven reforms that are in place in California and Texas and other innovative solutions;
• Continue progress with medical innovation by prioritizing funding for the National Institutes of Health, adopting a 21st Century Cures Act 2.0 initiative to support pioneering medical technology and life-saving therapies and expanding the availability of telehealth;

• Alleviate the burdens of electronic health records (EHRs) by achieving interoperability, preventing data blocking, reducing unnecessary data entry and improving the functionality of EHR systems to enhance, not hinder, the delivery of medical care;

• Restructure Medicare quality improvement programs by minimizing the complexity, streamlining and reducing reporting burdens and promoting specialty-specific quality measures, clinical data registries and alternative payment models that clinicians, not the government, develop; and

• Champion fair reimbursement by improving the Medicare physician payment system — including providing an inflationary payment update, revisiting budget-neutrality requirements and maintaining the 10- and 90-day global surgery payment package — empowering patients and physicians to privately contract fee arrangements and closing the gap in payments between Medicaid and private insurers to reduce access to care disparities.

• Provide direct input into National Institutes of Health strategic planning through specialty-wide consensus of One Neurosurgery Summit member organizations (CNS, AANS, the American Academy of Neurological Surgery, ACGME Neurosurgery Residency Review Committee, and the Society of Neurological Surgery).

To read more about the Washington Committee’s most recent efforts around prior authorization, be sure to check out Katie Orrico’s article on page 20.

Current Washington Committee members and subcommittee chairs

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<th>Position</th>
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<tr>
<td>Chair</td>
<td>John K. Ratliff, MD</td>
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<td>CNS Appointees</td>
<td>Maya Babu, MD, Alexander A. Khaleesi, MD, Russell R. Lonser, MD</td>
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<td>CNS Ex Officio</td>
<td>Brian L. Hoh, MD, CNS president, Nicholas C. Bambakidis, MD, CNS President Elect</td>
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<td>AANS Appointees</td>
<td>John D. Davis, IV, MD, Joshua M. Rosenow, MD, Luis M. Tumialan, MD</td>
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<td>Regis W. Haid, Jr., MD, AANS President, Ann R. Stroink, MD, AANS President Elect</td>
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<td>Coding and Reimbursement Committee chair</td>
<td>Joseph S. Cheng, MD</td>
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<td>Communications and Public Relations Committee chair</td>
<td>Clemens M. Schirmer, MD, PhD</td>
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<td>Joint Guidelines Review Committee chair</td>
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<td>Neurosurgery Quality Council chair</td>
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AANS/CNS Washington Committee for Neurological Surgery

The Washington Committee volunteers and staff work on behalf of our members to make it clear to policymakers in the nation’s capital that we are dedicated to advancing neurological surgery and promoting the highest quality of patient care, training and research. You should feel assured that organized neurosurgery remains at the heart of critical debates impacting your patients and practice.

To follow the work of the Washington Committee, visit the committee’s web hub at www.neurosurgery.org. You will find links to the committee’s social media accounts, key coalition partners and neurosurgery’s Advocacy Action Center — where you can track progress on top advocacy issues and show your support for neurosurgery’s legislative agenda by contacting Congress.

Please do not hesitate to reach out with feedback or if you would like to get involved.

Resource

Equity, diversity and inclusion (EDI) efforts within the field of neurosurgery may pale in comparison to the many larger initiatives, as many across the globe are beginning to stand up against institutionalized racism that has resulted in the premature death and subjugation of countless Black men and women. Committee meetings have a certain level of expected behavior that can water down sensitive discussions about inequity, racism and lack of diversity.

The efforts by the CNS to address EDI using the committee structure have been designed to include a core group of people who have a level of understanding amongst each other to foster intimate conversations, allowing for vulnerabilities and discussion of difficult topics. The newly formed EDI committee in the CNS spent some time discussing what exactly EDI meant for neurosurgeons. Understandably, the topic can generate many viewpoints. Just amongst a group of highly accomplished neurosurgeons with personal experiences related to discrimination and exclusion, a discussion about EDI included race, gender, sexual orientation, practice type (academic versus hospital employed versus self-employed private practice), socioeconomic, and more. The definition of EDI can be endless which may result in a lot of work without achieving the short term wins that are critical for gaining momentum.

To achieve tangible results in a short period of time, the CNS EDI committee has chosen to focus on three overarching goals including 1. Addressing implicit bias and diversity within the CNS Executive Committee, 2. Ensuring diversity and equity in and for CNS membership, 3. Lowering barriers to recruiting a diverse neurosurgical residency applicant pool. These goals are supported by concrete milestones with measures of success and failure. To ensure success in addressing each goal, the EDI committee is now recruiting a dedicated group of individuals who will push these forward and help mold the future of the CNS in the context of significant social change.
The first goal of addressing implicit bias has resulted in two educational programs developed for 2021. The first, is a longitudinal program to enhance awareness of implicit bias amongst CNS Executive Committee members. This included working with consultants to develop a program for the CNS executive committee summer meeting. In preparation for the program, several EC members participated in Project Implicit (www.implicit.harvard.edu) which provides free modules to assess your personal biases. In each module, users must rapidly select pictures and words they assess as either positive or negative. The time it takes you to respond is measured and used to determine if you have a preference of one group of people over another. The modules are very revealing because biases are prevalent amongst all of us – good people have biases. Awareness of these biases allows you to intentionally surround yourself with a team that can help avoid blindspots by a single person. In addition to efforts with the CNS Executive Committee, EDI committee has developed programming at the CNS Annual Meeting in Austin to discuss implicit bias, with an afternoon session titled “Implicit Bias: How to Promote Equity in Neurosurgical Practice and Training.” This course will be the first of its kind and has a diverse faculty with different viewpoints to review the historical events that have led to inequity in health care system, case studies of how biases affect training, hiring and promotion in neurosurgery, and strategies to mediate implicit biases.

The third EDI goal for the CNS is one that has fostered collaboration with neurosurgeons and community leaders across the country. In an attempt to diversify applicants for neurosurgical residency, the CNS EDI committee has developed two programs: 1) Pathway to Neurosurgery and 2) CNS Community Engagement Program. The CNS Pathway to Neurosurgery program will have its inaugural event at the Annual Meeting in Austin in memory of Dr. Tim George who was the Chief of Pediatric Neurosurgery at Dell Medical School in Austin and passed unexpectedly in 2019. He was well-known for being an effective mentor and inspired many students from underrepresented backgrounds to choose neurosurgery as a career. In the Pathway to Neurosurgery program, local high school students from disadvantaged backgrounds will have a one-day immersive experience in the convention center alongside other annual meeting attendees. They will be eligible to apply for a one-year mentorship experience with one of the Dell Medical school neurosurgeons and a stipend. This program is being planned in collaboration with Rosalind George (Dr. George’s wife) and Breakthrough in Central Texas. The second program, the CNS Community Engagement Program, is being built to engage with neurosurgeons who want to work with local high school students to provide teaching in the classroom and mentorship. The CNS will provide materials to local neurosurgeons to be used in the classrooms and also provide awards to be distributed to select students that will provide a stipend and an opportunity to attend the CNS Annual Meeting with a parent/guardian. The pilot of this program will be lead by Dr. Sonia Eden in Detroit, MI.

Although committees and meetings seem vanilla compared to going to the streets to enact change, the CNS EDI Committee is working on systematic changes in educational programming, nomination processes and opportunities to students who are otherwise left out, to provide a platform for sustained change over time. If you are interested in joining this effort and are willing to roll up your sleeves to do some work, we would be happy to hear from you.

The how and why of advocacy work surrounding racial disparities in neurosurgery is layered, complex, and, in many ways, mirrors the practice of medicine itself. Indeed, to find a solution one must recognize the problem and endeavor to thoroughly understand it. Unfortunately, there isn’t one thread that can unravel how we got here, nor will there be a single solution. However, there are systematic practices that can be addressed in real-time to get us closer to a diverse and equitable Neurosurgery.

The why of this work involves understanding the timeline, the actions, and events that have led to this moment in health care, in our field of neurosurgery, and in society. Many believe that, for too long, we have ignored the smoke and now we are trying to put out a much larger fire. The smoke is metaphorically represented in various racial disparities that have long existed. In health care, this includes inequitable access to care, racially discordant outcomes, life expectancy, maternal morbidity, and mortality. Disparities in the criminal justice system are reflected by disproportionate rates of mass incarceration, use of excess of force in police encounters, and fewer opportunities for rehabilitation versus retribution for Black people. Disparities in the socioeconomic ecosystem are evident in policies such as redlining, predatory lending, voter restriction, and disparate rates of unemployment and underemployment in the Black community.

In 2020, disparate outcomes of the COVID-19 pandemic and racially motivated violence converged to create a true public health crisis. An apparent devaluation of Black life was amplified in the deaths of Ahmaud Arbery, Breonna Taylor, and climatically George Floyd. Black Lives Matter, while remaining a protest cry and rhetorical statement, did beg the question: who ever decided they did not? This perfect storm shed much needed light on the need for equity and true diversity in health care. It forced many, individually and collectively, to go beyond platitudes addressing how we can all do better, and truly ask why we are not doing better already? This isn’t the first time that we as a society have been compelled to address racism. So why does the urgency feel different today?

This brings us to the what in between the why and how of advocacy. Diversity is defined by the practice of involving people from a range of different social/ethnic backgrounds, genders, orientation, etc. It is quantitative rather than qualitative. In recent years, neurosurgery, like many fields in medicine, has made enormous strides in increasing the numbers of women and underrepresented minorities within the field of practice. However, the face of leadership, power, and influence has maintained a rarely altered white balance. Playing a numbers game makes for a better group picture but does not change the view through the lens. This calls for a transition from diversity efforts towards the achievement of equity, a qualitative principal. This very conversation is often uncomfortable because those who have enjoyed the privilege of the status quo—knowingly and unknowingly—must intentionally share that privilege with those who have been historically left out. In the case of neurosurgery, it...
involves the more proportionate distribution of power and influence used to affect the trajectory of the field.

Furthermore, altering the power dynamics within the leadership structure of neurosurgery can have downstream effects on how Black people are recruited and retained in neurosurgery, through intentional introduction and exposure of young Black professionals to the field. Further, creating an equitable environment involves addressing the way in which Black trainees are treated and ultimately how they are promoted as attendings.

In addition, advocacy extends to the way in which we engage the Black community in the care we provide as neurosurgeons. It has been a source of historical debate that Black patients often have worse outcomes relative to their non-Black counterparts when it comes to heart disease, cerebrovascular disease, cancer, etc. This may be reflected, for example, in the degree to which Black patients are involved in clinical trials leading to the establishment of treatment protocols and management guidelines in neurosurgery. One may extrapolate that this inevitably affects overall clinical outcomes to a degree that has yet to be fully studied and understood in the field of neurosurgery. There is a paucity of literature investigating the difference in outcome for Black patients with various neurosurgical pathologies. Are we serving the Black community in the best way, and how are we measuring that?

So how do we establish the advocacy we describe? It is important to note, while this conversation has reared its head once again, this is a perennial discussion rarely ending in the sought-after transformation. While intentions may be sound, performative actions alter the appearance, but not the foundation of our systemic culture. We stop short of making institutional structural changes, while the hard work of uprooting structural racism and its inevitable manifestations remains undone. It is no longer enough to look good, we must actually be good.

While avoiding performative actions, we must be advocates of intentional or deliberate diversity. Here we must not stop at focusing on gender inequality, although relevant and deserving of endorsement. This more palatable form of inclusion has taken the place of addressing organizational racial bias, resulting in a laudable increase in the number of women in neurosurgery in the last decade. However, this is reflected in an increase in the number of White women in the field without the same growth reflected in the number of Black women specifically or Black professionals in general.

Structural change is reflected in measuring the problem adequately and coming up with specific solutions. This is a short but purpose-driven list of initiatives to address and reverse the manifestations of systemic and structural racism present in our society and consequently reflected in the field of neurosurgery.

1. A Diversity and Equity Task Force that is commissioned to collect the data that reflects the number of Black people recruited and retained in the field of neurosurgery each year. In addition, it would optimally challenge the field of neurosurgery with annual task-oriented goals to alter the baseline.
2. Reflecting the diversity of neurosurgery has to be present in the face of organized neurosurgery. Inviting Black neurosurgeons into the spaces of leadership within our organizations like the CNS, AANS and our training programs as chairs and program directors would be an important first step.
3. Supporting the work of studying the disproportionate outcomes in neurosurgical pathology within the Black community with earmarked research grants and awards.

Over the years, because of historical disparities in neurosurgery and health care, many recognized the need for an organization with a realistic perspective on racial issues that affect neurosurgery. Over the past year we have helped organize a group of concerned and energetic neurosurgeons to lead the charge to focus our collective advocacy efforts. It began with a group of nearly 100 Black neurosurgeons and culminated in the incorporation of the American Society of Black Neurosurgeons (ASBN). The mission of ASBN is to improve public health by supporting Black neurosurgeons and enriching the equity and integrity of neurosurgical care. The historical endeavor of bringing together Black neurosurgeons serves to provide a unique perspective in the championing of reform within the field of neurosurgery. ASBN seeks to amplify the voices, issues, and concerns that have not traditionally been in the forefront of organized neurosurgery.

Ultimately, we are all in the business of taking care of patients to the best of our ability, regardless of ethnicity, race, gender, or other systemic bias. However, we are subject to the same bias that exists in society which can affect our ability to provide the best care. The focus of our advocacy efforts is to address prejudice as it affects patient and practitioner alike and, in so doing, facilitate the provision of high-quality neurosurgical care for all patients.
Bringing Selective Dorsal Root Rhizotomy to Ontario, Canada

The indications and techniques of dorsal rhizotomy have been evolving over time. As recently as March of 2021, an international debate comparing selective dorsal rhizotomy (SDR) and intrathecal baclofen was featured in the Clash of Titans series of the International Society for Pediatric Neurosurgery. Cerebral palsy (CP) is the most common cause of childhood physical disability and children with CP and spasticity face long-term functional limitations. Spasticity, a velocity-dependent increase in muscle tone, can impede ambulation when present in the lower extremities, and result in pain or discomfort as a result of uncontrolled muscle spasms. By permanently severing spinal sensory rootlets, dorsal rhizotomy can reduce spasticity by disrupting the spinal reflex arc. In the appropriately selected patient, SDR can improve function and mitigate long-term musculoskeletal sequelae.

In the early 2000s, SDR was no longer routinely offered for children in Ontario. As evidence of the benefits of Botulinim toxin injections became available, treatment had shifted to offering the less invasive injections for eligible children. There were only two other large cities in Canada, Vancouver and Montreal, that have been providing SDR consistently. Occasionally, families in Ontario considered travelling abroad to receive SDR. However, this option came at great personal expenses to families, partially due to the medical and travel costs as well as time away from employment for the required physiotherapy that followed the surgery. Some families were able to apply for reimbursement from the Ontario Health Insurance Plan (OHIP). Many families also turned to GoFundMe campaigns, raising awareness online regarding CP and SDR. The end result, however, was limited options and prohibitive cost for many families, leading to inequitable access to care.

Parents of children with CP expressed frustration to physicians and also the media, to have SDR and travel expenses fully covered through OHIP. Physicians heard their call and came together to discuss. A group of provincial neurosurgeons, orthopedic surgeons, developmental pediatricians and neurologists reviewed the evidence regarding consensus criteria for children who would benefit from SDR. A randomized control trial from Toronto had demonstrated that for children with spastic diplegia, there was improved function at 1 year with SDR and physiotherapy compared to physiotherapy and occupational therapy. Furthermore, with evolving techniques, SDR could be performed through a smaller laminectomy with electrophysiology to help identify rootlets to cut. In carefully selected patients, SDR had the potential to be beneficial in improving function and quality of life in specifically selected children with CP. These collaborations sparked the recognition that SDR should be offered in Ontario directly.

Once healthcare practitioners became allies recognizing the need to bring SDR to Ontario, the decision to seek funding from the Ministry of Health required an extensive proposal. The original physician team consisted of developmental paediatricians, Dr. Golda Milo-Manson and Dr. Darcy Fehlings from Holland Bloorview Kids’ Rehabilitation Hospital and Dr. James Drake and Dr. Unni Narayanan from SickKids neurosurgery and orthopedic surgery respectively. It was clear to the physician team that simply funding the surgery would not be enough; a formalized rehabilitation regimen following surgery would also need to have guaranteed financial support. The idealized Ontario SDR program would utilize updated evidence and knowledge from current sites providing SDR. As such, a multidisciplinary team took the time to visit, observe and learn about optimizing the surgery and the programming related to inpatient and outpatient physiotherapy regimens. This working group—strongly influenced by patient and parental feedback—put together a proposal for the government to support SDR and subsequent physiotherapy for one year following surgery.

The government, through Health Quality Ontario, performed a detailed and thorough health technology assessment in 2017. This

> ADVOCACY IS A TEAM SPORT. ADDRESSING AND BALANCING CONCERNS OF EQUITABLE ACCESS, EVIDENCE-BASED PRACTICE, AND FUNDING IS A LARGE UNDERTAKING. THE GROWTH AND SUCCESS OF THE ONTARIO SDR PROGRAM HIGHLIGHTS THE VALUE OF WORKING IN PARTNERSHIP WITH FAMILIES AND TO THE GOVERNMENT <
review included several assessments focused on clinical outcomes, economic evaluations, and also a qualitative analysis of the lived experience of caring for children with CP. The cost of the Ontario SDR program was estimated to be $1.3 million dollars annually. In December of 2017, OHIP approved funding for 12 children through the SDR program from the Hospital for Sick Children and Holland Bloorview Rehabilitation Hospital. After clinical evaluation by the multi-disciplinary team, the first child received an SDR through this new program in January of 2018.

![Figure 1: Headlines regarding the introduction of SDR to Ontario](image)

The SDR program was originally made eligible to children ages 4-8 with spastic diplegic CP with the goals to help patients stand, walk or run. The initial assessment is made by a neurosurgeon (currently Dr. George Ibrahim), a pediatric rehabilitation specialist (Dr. Milo-Manson or Dr. Fehlings), a physiotherapist, an orthopedic surgeon (Dr. Unni Narayanan or Dr. Mark Camp) and a registered nurse. Children who receive surgery at the Hospital for Sick Children will have a 3-month inpatient and/or day-patient rehabilitation period. Up to 12 months following surgery, children receive physiotherapy in an ambulatory setting at their local centers. There was a coordinated effort to educate all outpatient centers through webinars and workshops to ensure standardized physiotherapy over all sites.

Currently, the Ontario SDR program funds 17 patients annually to receive SDR, and subsequent rehabilitation. Although SDR is traditionally utilized as a procedure to improve ambulation in children with CP who are functioning at Gross Motor Function Classification System (GMFCS) Grades I-III, could the surgery also help reduce pain that is caused by spasticity in non-ambulatory children (GMFCS IV-V)? SDR has the potential to positively affect sitting balance, toileting, and even sleep, although definitive evidence is still required.

The success of bringing SDR to Ontario is only the beginning of advocacy efforts. Many provinces still do not have access to SDR and questions regarding access and funding for out-of-province patients require careful consideration. Recently, Australia and England embarked on a national approach to incorporate SDR as a centralized specialized service with one center in Australia and five centers in England. The Canadian Collaborative on Best Advanced Treatments for Cerebral Palsy (CanBeAT-CP) was established with the hope that a national strategy can be created to address ongoing inequities in access.

Advocacy is a team sport. Addressing and balancing concerns of equitable access, evidence-based practice, and funding is a large undertaking. The growth and success of the Ontario SDR program highlights the value of working in partnership with families and to the government. SDR has been positive for many children in Ontario with CP.

References:
Social Entrepreneurship and Healthcare Advocacy

In January 2011, millions of Egyptians took to the streets to protest then-President Mubarak’s authoritarian regime. All eyes of the world were on Tahrir square in the heart of Cairo where peaceful protesters camped. In 18 days, the whole dictatorship collapsed, and a new era started in the Middle East—dubbed the “Arab Spring.” I joined some of these protests, and worked as an intern physician at one of Egypt’s busiest academic health centers the days I was not in the streets. Shortly after this period, a heightened sense of community service and patriotism was spreading amongst Egyptian youth and I wanted to capitalize on this once-in-a-lifetime opportunity.

Along with a small group of colleagues, I started a non-profit named “Healthy Egyptians.” We planned to focus on what we understood: health care. At that time, being involved with a non-profit or a “non-governmental organization” (NGO) was a scary endeavor in Egypt—such activists were frequently the targets of undue scrutiny and harassment by the security apparatus. As a result, I could not find ten people willing to go forward and provide their names in the legally required paperwork needed to set up our non-profit. So I convinced my mother, brother, and then-fiancée to join as co-founders.

Entrepreneurial Approach

Healthy Egyptians sought to approach healthcare problems using innovative solutions. We tackled healthcare issues as entrepreneurs approach a new market. Markets respect a fundamental rule: demand and supply. If there is no perceived demand for our health awareness activities, no matter how passionate we were about our product, it would all be in vain. Mundane health educational campaigns were a no-go for us.

We decided to focus on children as our entry point into families. A parent might be reluctant to reduce smoking for their health, but more likely to respond for their children’s wellbeing. Our services, therefore, needed to be attractive, innovative and at the same time be evidence-based. We also had to utilize technology and media to spread our messages to as many people as possible, using our limited resources. This is not an easy task in a country with a high illiteracy rate—29% in 2017, according to the United Nations Educational, Scientific and Cultural Organization (UNESCO).

After weeks of brainstorming, we created a cartoon character—a young boy called Montasser (Arabic for “Victor”) who solves health mysteries with the help of his special scientific arsenal and his doctor friend. This was marketed to children using platforms including: coloring books, puppet shows, role-playing games, cartoon movies and video games. Our movies were high-quality and provided free to satellite TV channels, aired during prime time to millions of viewers in the Middle East. When we realized few children in impoverished areas had access to those cartoons, we created a portable cinema truck with tiny chairs, a large screen, and a sound system, and drove it to their neighborhoods playing the cartoon while providing parents with further educational materials as they waited for their children. In two years, the organization that started with a thousand-dollar personal donation reached thousands of beneficiaries and was featured in the Financial Times. We were able to recruit and train hundreds of medical students and school teachers across the country. Moreover, we created strategic partnerships with pharmaceutical companies to provide life-saving vaccines, worth millions of U.S. dollars, free of charge to underprivileged children. Merely donating those vaccines to impoverished neighborhoods without creating a demand through our educational activities would have meant such vaccines would have gone to waste.
Challenges
To add to our challenges, we had to fight back against misinformation aimed at convincing the public that vaccines outside of the National Immunization Program (NIP) were dangerous. Decisions to add vaccines to the NIP are mainly economical, and until the country adds important vaccines such as the pneumococcal or Haemophilus influenzae vaccines for millions of newborns, only those who can afford them are able to protect their children against those deadly diseases.

Financial stability is critical for non-profits and often a limiting factor to their impact in the community. Beyond our corporate partnerships, we won several grants from institutions such as Johns Hopkins Bloomberg School of Public Health, Grand Challenges Canada, and the United Nations. However, “foreign funding” was usually frowned upon by the security apparatus, and in many cases, the funds would be locked in our bank account until security approval was obtained—usually long after the grant’s deliverables’ deadline is reached. We tapped into other organizational funds to carry out our projects while we awaited approvals. In fact, I first met my wife when she was the editor-in-chief of the American University in Cairo’s newspaper. She reached out to write a story about my advocacy work, but when she learned that writing about “foreign funding” I had received from Johns Hopkins might get me into trouble, she decided to never run the story. Nevertheless, I kept in touch with this intellectual, beautiful journalist and—even though our relationship started with self-censorship—I remain grateful to have met her.

Global-Local Partnerships
To maximize our organizational influence, we created coalitions with local and international non-profits such as Save The Children, which had the resources to transport volunteers to the most remote areas of Egypt and spread our health awareness tools further than our limited resources allowed. Such symbiotic partnerships between a local organization like Healthy Egyptians and an international organization, proved crucial to achieve both organizations’ missions. It also goes to show the impact global entities headquartered in the U.S. can have even in a remote Egyptian village. For the highly specialized, life-saving discipline of neurosurgery, similar collaborations could be highly conducive for global neurosurgery, perhaps in addressing neurosurgical problems such as traumatic brain injury, which exert a heavier burden on resource-limited countries compared to the developed world.

Sustainability
What is more important than conducting healthcare advocacy, is finding ways to make it sustainable. Whenever we approached schools or daycares, we would train their teachers on delivering health educational messages. We also integrated our health educational curricula in some of these schools, so our mission would carry on, even if the organization or its people change. We partnered with academic institutions where researchers studied the impact of our educational tools on information retention amongst children. We also realized how critical it is for our mission to direct some of our advocacy activities towards policymakers. In less than two years, one of the two vaccines we were advocating for, H. influenzae type B, was introduced into the Egyptian NIP. While we can’t attribute such a milestone to Healthy Egyptians, we take pride that we were one of the very few voices advocating for this step at the time.

Despite all the challenges, we were always driven by a common vision and passion. As most good things usually come to an end, in 2019, the Egyptian Parliament passed new legislation that our Board Members found to be too restrictive on our public health activities within the community. To protect the freedom and safety of our volunteers, the board unanimously voted to permanently close the organization, and donate the remaining funds to the Egyptian Ministry of Social Solidarity to be used to support other non-profits. It was one of the hardest decisions I have had to make, but I like to view it as the end of a chapter rather than the whole book. The experiences, lessons and friendships I have made in this chapter were invaluable and will forever shape my approach towards healthcare and advocacy.

I dedicate this article to the amazing team of truly dedicated people who made Healthy Egyptians such a beautiful place to belong to.

Dr. Mohamed A. Zaazoue is a PGY5 neurosurgery resident at Indiana University School of Medicine. He is an Ashoka fellow and was named as one of the 30 most influential people under 30 in the world in the field of social entrepreneurship in Forbes’s “30 Under 30” yearly list in 2014. He served as an adviser to the Egyptian President for community development and healthcare reform between 2014 and 2015.
“Do you have any way of getting in touch with our patient? I have a critical result from his lumbar MRI.” I listened to the concerned voice of my colleague, a neurosurgeon who had just imaged our mutual patient with neurofibromatosis. A spinal lesion was found to cause cord compression, and we needed our patient to present to the emergency room right away.

This was a patient both the neurosurgeon and I, from my role as primary care physician, had worked fastidiously with over the course of years. His access to care was limited by socio-economic barriers. He had poor insurance. He was economically unstable and already concerned about losing his job—a concern that only increased as we began to ask him to come for more and more tests and appointments.

Neurosurgeons may not be the first specialists that come to mind when one thinks of physician advocacy. But as this case shows, neurosurgeons are well positioned to serve in this vital role. Physician advocacy has been defined as “action by a physician to promote those social, economic, educational, and political changes that ameliorate the suffering and threats to human health and well-being that he or she identifies through his or her professional work and expertise.”¹ Our patients trust us to be part of critical moments of their lives, granting us a unique vantage point from which to understand how broader social and structural factors impact their health and well-being.

As the co-director of the Center for Health Equity Education & Advocacy (CHEEA), advocacy has been central to my work and professional development. CHEEA’s teaching philosophy is driven by five objectives: 1) to clarify and further develop the values that brought health professionals to the care of marginalized populations; 2) to elucidate the role health professionals can play in addressing systemic health inequities; 3) to improve knowledge of topics in health systems, equity, social determinants of health, and health policy; 4) to develop skills in research, community organizing, leadership, and health advocacy; and 5) to provide mentorship and role modeling to support career development that incorporates health advocacy. CHEEA’s pedagogy is anchored in longitudinal and experiential learning, and reflective practice.

We believe robust advocacy training will not only improve knowledge and skills in health equity and advocacy, but will help clinicians lead values-based careers and create a workforce that is humanistic, resilient, and empowered to better improve health equity. We also have found that our programming can increase connection to community, a sense of purpose, self-efficacy, and joy in the workplace.

It can feel hard to begin incorporating advocacy into one’s career, but I have found two frameworks consistently valuable to me as I have integrated advocacy into my work. The first is the framework of structural competencies, defined as the capacity for health professionals to recognize and respond to health and illness as the downstream effects of broad social, political and economic structures.² Structural competencies were first defined by Metzl and Hansen³ in a new paradigm for medical education, emphasizing a systemic and upstream analysis of what we see in our clinical work. Many of us have experienced frustration seeing our patients suffer from preventable illness because of a lack of a social infrastructure promoting health. In my work as a primary care physician, I see daily the impacts of poverty, racism, environmental injustice and impaired healthcare access. The structural competency framework has been helpful to me in “diagnosing” the upstream factors impacting my patients and has informed the advocacy projects I take on. One can likewise imagine neurosurgeons caring for head trauma patients identifying unsafe work conditions that may expose patients to unnecessary risk of severe disease, and advocating for a change in occupational health policy.

The second framework that has significantly informed my work is public narrative, a community organizing skill set. Public narrative is a storytelling craft that Harvard Kennedy School Professor Marshall Ganz defines as “an exercise of leadership by motivating others to join you in action on behalf of shared purpose.”⁴ Ganz emphasizes the importance of storytelling in community organizing because it enables a focus on shared values, shared experiences, and shared purpose in making change. “Stories,” he says “are how we learn to access the moral and emotional resources we need to face the uncertain, the unknown and the unexpected.”⁴

Too often in medicine, we neglect the fact that sharing stories, and the emotions that they elicit, is critical to making change. I have found that having both robust data and effective storytelling skills is a valuable way to convince decision makers to make change. Public
narrative has three major components: story of self, story of us, and story of now. The central purpose of the story of self is to present why you are called to serve and to define the values that motivate you. Story of us focuses on defining the values, experiences, and aspirations of one’s community. And story of now makes the argument for the urgent challenge that must be confronted, illuminating a pathway towards a more hopeful future.4

Thus, taken together, structural competencies and public narrative have provided me with concrete skill sets to better diagnose the upstream structural factors impacting my patients, and to address them by using effective storytelling to persuade policy makers and decision makers to make change.

But these skills sets mean little if clinicians lack the resources to nurture their interests in advocacy. My work at CHEEA has taught me the value of having dedicated time in which clinicians can receive the enrichment, community and skill building that comes out of coursework. I encourage my colleagues to find a course in which they can have a longitudinal experience. And that must only be the beginning. Mentorship is critical to finding ways to incorporate advocacy into clinical careers. Having a community in which advocacy interests can be supported and cultivated will make it far more likely that one can invest in this work. And that means that institutions must create protected time for clinicians to learn advocacy and work on projects that will improve health equity.

The practice of modern medicine is nothing short of a miraculous endeavor. I have watched my colleagues in awe, amazed by the extraordinary ways they can help people live longer, healthier lives. But we must invest more meaningfully in the work of cultivating advocacy skills and advocacy careers in medicine. Doing so will help us address the broader structural and social factors profoundly impacting our patients.

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An Interview with a Caregiver

Ginny and Dan have been married for 43 years. Their lives changed in many ways when Dan was diagnosed with Parkinson’s Disease (PD) in 2011. Self-advocacy eventually led to Dan obtaining the specialized help he needed to manage his disease. Recognizing the limited resources available to patients and caregivers, they have become actively involved in patient and caregiver support groups, advocating for timely diagnosis and management and for development of strong social support networks.

I sat down with Ginny to get her perspective of the challenges and burden that caregivers experience when a loved one is diagnosed with a chronic illness.

Q. What was your reaction to the diagnosis?
A. Dan had his tremor for a long time, and it took a while to get a diagnosis. It was kind of a gradual, growing awareness into the diagnosis. Dan was the first to embrace it and wanted to learn more and get involved. I fought it for a long time. I think I had to grieve the loss of the kind of life I thought we were going to have, and I had to process all my sadness and anger before I made peace with it.

Q. How has the diagnosis changed your relationship?
A. We have always been close and done a lot together, but also have independent interests and have been able to pursue those. We do more together now, which can sometimes feel burdensome. But with Dan being home-bound, I can understand his need to want to do more on the weekends. It is also stressful because we have always had specific roles in the relationship which have changed. We are still working towards finding our balance. The key I feel is being patient and forgiving.

Q. Do you feel your work burden has increased and you are sacrificing more of what is important to you?
A. He does A LOT! I haven’t felt like I am taking care of him even though he doesn’t do some of the things he used to before. He has taken on new responsibilities which have evened things out somewhat. I have noticed he has withdrawn socially. He was always the more social one but now with his apathy and lack of energy it is hard for him to keep up with conversations. It has affected our social life since he was always the one who took the lead in relationship and friendship building.

Q. How has this change in your social life affected you?
A. It has been hard. I want people to know we are still here and value doing things. We sent a letter with our Christmas card last year where Dan wrote “I may look different and there may be times when you’re unsure of what I am thinking or feeling- but please be patient with me. I might not respond as quickly as you’re used to, but I am still me.” Our friends were very appreciative. It was hard to be...
vulnerable but since then friends have stepped up with that insight. Honesty helped.

Q. What do you miss the most?
A. I feel like I have lost my partner a little bit. He always had a quick wit and a loud laugh and there are times when I just do not see that anymore. I am grieving the little losses even though he is still here. I want to be grateful, but it can be hard sometimes. He is a little pricklier than he used to be. For instance, we went hiking with some friends and I suggested walking further, but he said “no.” I was really upset with him until he told me “I already feel worthless enough.” It was because he was too tired to keep going but I cannot see tired. We were able to then discuss that he needs to tell me what he is experiencing. My takeaway is when he DOES tell me something I need to acknowledge it and understand what lies behind his decisions. On a few occasions, I have gone further while he rests and while I feel somewhat guilty, I must get ok with that, so I don’t get resentful.

Q. What scares you the most?
A. Potential for cognitive decline leading to isolation and losing friendships. I fear sometimes that I will not be up to the task emotionally or have the compassion that I need to support him.

Q. What are some of your coping strategies?
A. I realized a few years ago we had let our world get very small and we were hyper-focused on PD. We had to go back to being ourselves and, for my sanity, we needed to reach out to our friends and tell them we needed to be included. This has been helpful. Our support group has been exceptionally helpful, especially the care partners, where I can be open and honest without fear of judgement. I have picked up older hobbies and am trying to go back to who I was and do things that I used to enjoy. I do see great value in connecting with other care partners who can walk through the PD journey with me. It’s helpful to have people who will just listen and empathize and who understand that in some ways it’s harder to be the partner than the patient. You are not only mourning for them but also for yourself; your life has changed forever, and you will likely be the one dealing with the long-term consequences.

Q. Was it stressful navigating DBS surgery?
A. Making the decision to retire prior to his surgery was helpful but at the same time very difficult for Dan since he really enjoyed his work. We approached the surgery with a lot of excitement since we knew it was likely to help him a lot. The results were dramatic, so we are glad we did it. Seeing him vulnerable laying in the hospital bed was hard, but we had tremendous support throughout that process.

Q. What do you wish people around you would stop doing?
A. It is frustrating when outsiders see Dan doing well after DBS and then insinuate that the battle is over. It’s difficult to explain the daily challenges to them without seeming ungrateful. Or those well-meaning optimists who always tell you that you’re doing a wonderful job, but on the inside, you know you’re not doing all that great.

Q. What advice would you give to people starting off in a caregiver role?
A. Put things in perspective, don’t jump immediately to the worst-case scenario; this is a journey, and it may be a long one. Find, or as in our case, start, a support group. See a specialist. Our first visit with a Movement Disorder Specialist (MDS) was really an eye-opening experience and something that we had to actively advocate for. The neurologists Dan had seen previously took the stance that, “yes, you have PD, it will get worse over time and there isn’t anything you can do besides take medication”. The MDS really focused on how PD was impacting Dan and what could be done to improve his quality of life, especially tremor and speech. After starting the prescribed speech therapy, Dan discovered he was able to sing again – his volume, resonance and breath control were all markedly improved. In addition, he was having trouble with word finding and was fearful that this was the beginning of a cognitive decline. As someone with an extensive vocabulary who had always had the gift of finding the perfect word for any situation this was a huge loss. What Dan discovered though was that once he had mastered the mechanics of speech, the word finding difficulty was gone. Having a specialist who focuses on optimizing every aspect of Dan’s life has given us a new confidence that even though the disease will progress, there are many tools we can utilize to give us the best life possible.

Caregiver burden can be overwhelming. Advocacy groups and professional societies should focus on programs specifically aimed at easing caregiver burden by providing social support, education and financial counseling.
On Being a Self-Advocate

“You’re never as marketable or have as much leverage as when you negotiate a job.”

I remember being told this and not wanting to be “that person” who agreed to less than my value... yet I did. For me, learning to advocate for myself was a process that took years. Some key strategies I picked up through experience, others through formal development courses. I have also been fortunate to have many mentors to emulate who are skilled in this arena. I asked Julie Pilitsis, a friend, colleague, and mentor to share her insights and how she became such an effective self-advocate.

EA: When did you realize that you had to become your own advocate?

JP: As the eldest of two daughters of an immigrant, I think the idea of advocating for myself was instilled in me from an early age. I would say however it has been a lifelong process that I continue to develop. My husband and I have tried to instill similar skills with our children. I was very proud of my 11 year old daughter when she met with her soccer coach after practice to enumerate the goals and assists she had in the previous games as means of advocating for herself to get more playing time. I think it is important that we practice these skills with all our sons and daughters and mentees. Of course, you must have the production in order to be able to quantify your value.

EA: Did you receive any mentorship on advocating for yourself? What the key points?

JP: Absolutely, I vividly remember meeting Luanne Thorndyke, Executive Vice Dean at USC, and describing to her what I wanted to do with my life in a circuitous way. She said “So you want to be a chair?, Next time just say that.” Being direct about my goals has generally served me well. I also have worked with Laura Gruenthal, former President of Union College Graduate School, who helped me to actualize those goals. They both encouraged me to obtain formal training through institutional junior faculty development programs and external courses such as the Harvard Leadership course and ELAM.

EA: You have many mentees; how do you mentor them to be advocates for themselves?

JP: I received a thank you card from a mentee today that really touched me. It said “Everyone in neurosurgery has someone who made them go from ’I think I can’ to ’I know I can.’ You are that person for me.” I try to help my mentees recognize and then actuate their goals, similar to what my mentors have done for me.

EA: I often think of self-advocacy containing a negotiation element. In other words, understanding the person to whom you need to advocate, and their goals, should be applied to your advocacy strategy. Does this resonate with you? How do you adjust your approach for specific situations?

JP: I am currently an Executive Leadership in Academic Medicine fellow and one of the exercises we recently participated in, assigned us to simulate our behavior in various roles in an organization- top, middle, and bottom. A light bulb clicked for me and I realized that much of what you can do to advocate for yourself depends on what your role is in the organization and whose support you have. Generally, by support, I mean someone in a higher “rung” in the organization, though it doesn’t have to be. There is a current societal push for women to know their own value. I would augment this by noting that value may vary from situation to situation—it is a negotiation as you suggest.

EA: Some may view advocacy as an episodic process, such as advocating for a specific thing on a specific day. What are the ways you advocate for yourself on a daily basis?

JP: I tend to employ relationship building strategies as opposed to transactional strategies when advocating for myself and my team. Thus, keeping in mind overarching personal and professional goals and mission is paramount. As a female neurosurgeon, sometimes my default mode is to advocate for myself, as I have had to do that to get where I am. However, once you reach a certain level, a grace over grit mentality may be more appropriate. To directly answer the question however, I introduce myself as Dr. P or Dr. Julie to advocate for future generations of women doctors. I also keep a close eye on my calendar to make sure I can get done what is needed to remain true to my overarching goals. ■
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Medtronic
Delays and Denials: Neurosurgery Leads the Charge to Streamline Prior Authorization

The patient had weakness in her lower extremities and neurogenic claudication with severe spinal canal stenosis. Her health plan refused to approve lumbar decompression claiming my office did not send them the MRI radiology report. After we explained that we indeed did send the report, they found it but nevertheless told us that the time for appeal had passed and we had to resubmit the request. Several weeks passed without any response from the health plan, and the patient ended up in the emergency department with cauda equina syndrome and urinary incontinence.

The patient had a brain mass, and we scheduled him for a needle stereotactic guided biopsy. The health plan approved the surgery but refused to approve the stereotactic protocol MRI. I had to go through two peer reviews to explain why we needed a specific MRI for planning the biopsy that was different from the diagnostic MRI performed few days prior.

For most neurosurgeons, these and similar stories illustrate the day-to-day hassles that neurosurgical practices face navigating prior authorization requirements. This cumbersome process requires neurosurgeons to obtain pre-approval for medical treatments or tests before rendering care to their patients. The process for obtaining this approval is burdensome and costly to neurosurgical practices, requiring neurosurgeons and their staff to spend an enormous amount of time each week negotiating with insurance companies. As a result, patients experience significant barriers to medically necessary care — even for treatments and tests that are eventually routinely approved.

When surveyed, neurosurgeons from across the country continue to identify prior authorization reform as the number one recommended advocacy priority for the Congress of Neurological Surgeons (CNS) and the American Association of Neurological Surgeons (AANS). It’s no wonder. Recent research\(^1\) confirmed that prior authorization is delaying access to necessary care. Wait times for prior authorization can be lengthy — typically taking between two to 14 days, but sometimes from 15 to more than 31 days. Prior authorization hassles can also cause patients to abandon treatment altogether. Finally, the research demonstrated that prior authorization has a negative impact on patient clinical outcomes. As such, the Washington Committee is leading the charge to pass federal legislation to streamline prior authorization.

Prior Authorization Legislation Gains Momentum

To bring needed transparency and oversight to the Medicare Advantage (MA) program, the CNS and the AANS joined forces with the Regulatory Relief Coalition (RRC). The RRC is a group of national physician specialty organizations advocating for reducing Medicare program regulatory burdens to protect patients’ timely access to care. The coalition’s top legislative and regulatory priority is prior authorization reform.

> Peer-to-peer level discussions are frequently unnecessary and unnecessarily delay surgical intervention. The clinicians we speak to are not specialty-specific and often have no idea about the proposed procedure. <

Privademic neurosurgeon in Midwest U.S.A
As RRC leaders, neurosurgery is collaborating with leading members of Congress — Reps. Suzan DelBene (D-Wash.), Mike Kelly (R-Pa.), Ami Bera, MD, (D-Calif.) and Larry Bucshon, MD, (R-Ind.) in the House of Representatives, and Sens. Sherrod Brown (D-Ohio), John Thune (R-S.D.) and Roger Marshall, MD, (R-Kan.) in the Senate — to advance the Improving Seniors’ Timely Access to Care Act. The legislation is based on a neurosurgery-supported consensus statement on prior authorization developed by leading national organizations representing physicians, hospitals and health plans.

The Improving Seniors’ Timely Access to Care Act converts the prior authorization reform consensus statement into a legislative blueprint that would:

- Establish an electronic prior authorization (ePA) program and require MA plans to adopt ePA capabilities;
- Require the Secretary of Health and Human Services to establish a list of items and services eligible for real-time decisions under an MA ePA program;
- Standardize and streamline the prior authorization process for routinely approved items and services;
- Ensure prior authorization requests are reviewed by qualified medical personnel;
- Increase transparency around MA prior authorization requirements and their use; and
- Protect beneficiaries from any disruptions in care due to prior authorization requirements as they transition between MA plans.

In the past two years, we made significant progress in mobilizing support for this legislation. Nearly 300 members of Congress co-sponsored H.R. 3107 or S. 5044, making it one of the most evenly bipartisan and widely supported health care bills in the 116th Congress. As the 117th Congress gets underway, we have hit the ground running. The legislation has been reintroduced in Congress, and H.R. 3173 already has more than 200 bi-partisan co-sponsors. The Senate is expected to reintroduce the bill soon. Upon reintroduction, John K. Ratliff, MD, chair of the Washington Committee, stated in a press release issued in support of the bill:

“Prior authorization is the latest tactic that health plans are using to cut costs, but its rampant overuse is now causing inappropriate delays and denials of medical treatments that our seniors need. Neurosurgeons take care of very sick patients who suffer from painful and life-threatening neurologic conditions such as brain tumors, debilitating degenerative spine disorders, stroke and Parkinson’s Disease. Without timely medical care, our patients often face permanent neurologic damage, and sometimes death. The AANS and the CNS look forward to working with Congress and the Biden Administration to advance this bipartisan legislation, which will protect patients from unnecessary prior authorization, and we commend these legislative leaders for their efforts to rethink the entire prior authorization process for the betterment of our patients.”

A recent survey of neurosurgeons found the following:

- Eighty-two percent of respondents state that prior authorization either always (34%) or often (49%) delays access to necessary care.
- The wait time for prior authorization can be lengthy. For most neurosurgeons (67%) it takes between 2 to 14 days to obtain prior authorization, but for 22%, this process can take from 15 to more than 31 days.
- Prior authorization causes patients to abandon treatment altogether with 21% reporting that patients often abandon treatment and 60% reporting that patients sometimes abandon treatment.
- Overwhelmingly (88%), neurosurgeons report that prior authorization has a significant (37%) or somewhat (51%) negative impact on patient clinical outcomes.
- Ninety-one percent of neurosurgeons report that the burden associated with prior authorization has significantly increased over the past five years.

> Our practice is spending significant amounts of time and money dealing with prior authorizations. This burden increases every year, and as a result, our overhead goes up, and our current employees are forced to spend less time on patients and their care as a result. <

Private practice neurosurgeon in Midwest U.S.A.
The next step is for the relevant congressional committees — the Energy and Commerce and Ways and Means Committees in the House and the Finance Committee in the Senate — to take action on the legislation paving the way for Congress to vote on the bill later this year.

**We Need Your Help to Get this Legislation Across President Biden’s Desk**

To help expedite Congressional action, we need to demonstrate strong support for the legislation, which will better position the bill for committee and House/Senate floor action. While your Washington Committee and Washington Office staff are working tirelessly to get this bill to President Biden for his signature, we need your help. Congress must hear directly from neurosurgeons about the problems with prior authorization and the impact on patient care.

Neurosurgeons views and input are highly respected on Capitol Hill, so please take a few moments to send an email to your elected officials urging them to co-sponsor the *Improving Seniors’ Timely Access to Care Act*. You can go to the Washington Committee’s [Advocacy Action Center](https://fixpriorauth.org) to contact your Senators and Representatives. A sample message, which can be personalized, is provided. With your perseverance and assistance, this legislation will become the law of the land and will serve as a meaningful step in fixing prior authorization.

> With 100% of our appeals ultimately approved, it is clear that this process has not helped a single patient under my care and only delays their care with an unnecessary process delay loop. It has increased patient dissatisfaction, as well as provider dissatisfaction, frustration, and burnout.  

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**Additional Resources and to Take Action Visit:**

- Regulatory Relief Coalition: [www.regrelief.org](http://www.regrelief.org)
- AMA’s Fix Prior Auth Campaign: [https://fixpriorauth.org](https://fixpriorauth.org)
- CNS/AANS Advocacy Action Center: [www.neurosurgery.org](http://www.neurosurgery.org)
- Twitter: [#FixPriorAuth](https://twitter.com/hashtag/FixPriorAuth)

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The CNS Foundation is pleased to announce the winners of the inaugural Future Women Leaders in Neurosurgery Scholarship (FWLN), established by a generous gift from an anonymous donor and supported by many more.

**Beverly Cheserem**, Assistant Professor and Consultant neurosurgeon at the Aga Khan University Hospital, is from Nairobi, Kenya. Dr. Cheserem will allocate her award to attend, “Surgical Leadership Program” at Harvard Medical School.

**Kimberly Hoang** is an Assistant Professor in the Department of Neurosurgery at Emory University in Atlanta, Georgia. Dr. Hoang will allocate her award to attend the three-day online symposium, “Career Advancement and Leadership Skills for Women in Healthcare,” offered by Harvard Medical School.

**Sylvia Shitsama** is a consultant Neurosurgeon and a lecturer at the School of Medicine, Jomo Kenyatta University of Agriculture and Technology in Nairobi, Kenya. Dr. Shitsama will allocate her award to attend the three-day online symposium, “Career Advancement and Leadership Skills for Women in Healthcare,” offered by Harvard Medical School.

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    - HIIT Team Competition
  - Registration required on CNS Annual Meeting website. Limited capacity!

- **Tuesday evening, 6:30–8:00 pm**
  - **CNS FOUNDATION RECEPTION**
  - All CNS Foundation donors and awardees invited to attend as CNSF guests.

For more information and to register [https://foundation.cns.org/cnsf-in-2021](https://foundation.cns.org/cnsf-in-2021)

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NINDS-CNS Getch Scholar K12 Award Research Update

In 2018, Dr. Babacar Cisse was awarded the NINDS/CNS K12 Getch Scholar Award, a prestigious K12 Award offered through a unique collaboration between the CNS Foundation (CNSF) and the Foundation of the National Institutes of Health (FNIH). Dr. Cisse will present his work at the 2021 CNS Annual Meeting in Austin, TX. Named in honor of past CNS president, the late Christopher C. Getch, the award is a testament to the CNS’ commitment to fostering tomorrow’s neurosurgeon scientists. The CNS is a generous contributor to the CNS Foundation, making this partnership possible.

Transcriptional Regulation of Glioma-Associated Microglia
Isocitrate dehydrogenase-wildtype Glioblastoma (IDH-WT GBM), the most common malignant primary brain tumor, carries a poor 5-yr survival of 5% and a median survival of 15 months. Significant intratumoral cellular heterogeneity has thwarted efforts to fully understand IDH-WT GBM and develop effective therapies. Another major obstacle to a thorough understanding of IDH-WT GBM and development of effective therapies has been its unique and complex microenvironment. Tumor initiation, progression, response to therapy, and recurrence depend on regulatory signals that emanate from cells in the tumor microenvironment. Examples include microglia, tumor-associated macrophages (TAMs), and myeloid-derived suppressor cells (MDSCs) amongst others (Fig 1.). IDH-WT GBM is therefore considered a complex microcosm where complex interactions between neoplastic and non-neoplastic cells influence tumor formation, progression, response to therapy, and ultimate clinical outcome. Microglia are resident macrophages of the central nervous system (CNS) where they function as key immune effector cells in development, health, and disease. Recently, microglia have emerged as major players in the pathogenesis of various
CNS conditions; and microglia-directed therapies are an active area of research in neuro-oncology, neurodegeneration, stroke, and traumatic brain injury. In IDH-WT GBM microenvironment, microglia constantly interact with tumor cells and other constituents of the microenvironment; however, the intrinsic and extrinsic mediators and regulators of these interactions are still poorly understood. It is particularly not well known how specific transcriptional factors, such as E proteins, regulate the various spatial and temporal functions of microglia in IDH-WT GBM. E proteins or class I basic Helix-Loop-Helix (bHLH) proteins, which include TCF3, TCF4, and TCF12, are master regulators of various critical immune cells including B and T cells and plasmacytoid dendritic cells. TCF4 and TCF12 are expressed in murine microglia, and their null mutations are embryonic lethal. However, it is not known if TCF4 and/or TCF12 play any role in the development and/or functions of microglia in health brain and/or IDH-WT GBM. The selective expression of these master regulators in microglia justifies the critical need for elucidation of their roles in microglia. Elucidation of the transcriptional regulation of the functions of IDH-WT GBM-associated microglia would contribute to efforts to develop stroma-directed therapies, with the goal of combining such therapies with anti-neoplastic cell–targeted ones.

The long-term goal of our research is to develop more effective immunotherapies against IDH-WT GBM. However, we believe that the development of such therapies requires a better and more thorough understanding of the transcriptional regulation of microglia and other GBM-associated immune cells. Our work in the last three years has directed us to focus the role of a group of transcription factors known as E proteins in microglia. Two members of the E protein family, TCF4 and TCF12, are expressed in murine microglia, and their null mutations are embryonic lethal. However, unknown is the role of TCF4 and/or TCF12 in microglia in health and disease. The overall objective of this project is study the function of TCF12 in microglia in the microenvironment of IDH-WT GBM. In the last three years, we set out to specifically investigate the role of TCF12 in the normal development and function of microglia in mice. Our rationale was that determining the role of TCF12 in normal function and development would help predict and better understand observed phenotypes in TCF12-null microglia in normal brain and GBM. Due to the embryonic lethality of TCF12 mutation, we performed timed mating between heterozygous TCF12+/- mice to obtain null knockout (TCF12-/-) fetuses. One of the biggest challenges we faced was the fact that none of the TCF12-/- embryos lived beyond embryonic day 13.5 (E13.5). However, when we analyzed TCF12-/- microglia at E13.5 by flow cytometry, we observed an abnormal phenotype compared to the wild-type TCF12+/+ microglia. TCF12-/- microglia failed to mature properly as evidenced by upregulation of markers of immature microglia precursors. We also noticed upregulation of an immunosuppressive signature as a result of deleting TCF12 in microglia. We are currently performing transcriptomic profiling of TCF12+/+ and TCF12-/- microglia to gain better insight into the genes that are regulated by TCF12 in developing microglia.

We also have developed a conditional TCF12 knockout (KO) mouse in which the deletion of TCF12 can be induced specifically and temporally in microglia. The rationale for generating a TCF12 conditional knockout mouse is that it enables deletion of TCF12 before or after tumorigenesis. We added to the KO mouse a reporter gene that is specifically activated upon deletion of TCF12 in microglia. This helps tremendously in the identification, analysis and sorting of TCF12-deficient microglia. Another line of investigation that we have also been pursuing is the elucidation of the molecular mechanisms of TCF12 in microglia and identification of its target genes and binding partners. To the end, we have decided to use a novel murine microglial cell line called SIM-A9. The advantage of SIM-A9 is that it is an immortalized murine microglia cell line and not a transformed one. Using the Cas9-CRISPR system, we have successfully knocked out TCF12 in SIM-A9. Interestingly, our initial analysis of the knockout SIM-A9 cells showed upregulation of immaturity and immunosuppression genes. We are now in the process of performing transcriptomic, phenotypic and functional profiling of knockout cells compared to control cells. We are also using the SIM-A9 cell line to perform ChIP-Seq and mass spectroscopy studies to identify direct target genes and binding partners of TCF12 in microglia respectively.

Once we develop a better understanding of the role of TCF12 in the normal function and development of microglia, we will determine the effects of TCF12 deletion in microglia on the function in IDH-WT GBM microenvironment using murine GBM and human xenograft rodent GBM models. We hope to contribute to the elucidation of transcriptional machineries that drive the actions of GBM-associated microglia. We hope that our results will contribute to our understanding of the transcriptional regulation of microglia and constitute initial steps towards the identification of novel targets for stroma-directed GBM therapies.
Neurosurgery Leads Coalition Effort to Prevent Steep Medicare Cuts

On July 23, the CNS and the AANS joined more than 100 health care organizations to urge congressional leaders to avoid Medicare payment cuts in 2022. The letter — sent to House Speaker Nancy Pelosi (D-Calif.), House Minority Leader Kevin McCarthy (R-Calif.), Senate Majority Leader Charles Schumer (D-N.Y.) and Senate Minority Leader Mitch McConnell (R-Ky.) — thanked Congress for mitigating cuts that were scheduled to take effect in 2021 “via a 3.75% Conversion Factor (CF) increase for all services.” The letter noted that “the provider community is again bracing for steep cuts in 2022, which could result in many beneficiaries losing timely access to essential health care services. To avoid this scenario, our organizations urge Congress to maintain the 3.75% increase to the CF through at least calendar years 2022 and 2023.”

The letter also urged congressional leaders to consider reforms to the Medicare Physician Fee Schedule, including “addressing the budget neutrality requirement, which can lead to arbitrary reductions to reimbursement unrelated to the cost of providing care.” The letter stated that this requirement often results in providers being “forced into an adversarial role when fee schedule payment policies are developed and/or implemented.” Ultimately patients “suffer as providers adjust to unpredictable and excessive reductions to reimbursement that inhibit their ability to ensure beneficiaries have access to the care they need; services that improve outcomes and lower costs.”

“We remain committed to partnering with Congress to identify and advance these critical reforms and appreciate your continued support of the health care providers on which older Americans rely,” the letter concluded.

House Passes Health Spending Bill — Embracing Neurosurgery’s Priorities

On July 15, the House Appropriations Committee approved its $253.8 billion fiscal year (FY) 2022 funding bill for the Departments of Labor, Health and Human Services (HHS), Education and Related Agencies. The legislation was packaged into a broader spending bill, H.R. 4502, which passed the House on July 29 by a vote of 219 to 208. Some highlights pertinent to neurosurgery include:

- $49 billion for the National Institutes of Health;
- $612 million for the BRAIN Initiative;
- $400 million for the Children’s Hospitals Graduate Medical Education Payment Program;
- $25 million for the Pediatric Subspecialty Loan Repayment Program;
- $25 million for firearm injury and mortality prevention research;
- $43 million for opioids and pain management research at the National Institute of Neurological Disorders and Stroke;
- $15 million for traumatic brain injury; and
- $5 million for the Military and Civilian Partnership for Trauma Readiness Grant Program (also known as the MISSION ZERO program).

Other priorities include funding for the early detection of brain aneurysms and brain cancer research. Finally, the House has requested that the Centers for Medicare & Medicaid Services (CMS) report to Congress on the status of the Medicare Appropriate Use Criteria Program for advanced diagnostic imaging, including any challenges the agency is experiencing in implementing the program. The Senate has not committed to a timeline for its FY 2022 appropriations bills, increasing the likelihood of stop-gap funding legislation to avoid a government shutdown at the end of the fiscal year on Sept. 30.

Surgeons Urge CMS to Increase Global Surgery Code Values

On July 22, the CNS and the AANS joined 22 other surgical organizations in sending a letter to CMS objecting to the agency’s ongoing failure to value global surgery codes appropriately. In 2021, the values for new stand-alone evaluation and management (E/M) office visit codes were increased, but CMS did not adjust the E/M portion of the 10- and 90-day global codes. The continued refusal
to make these adjustments means that Medicare is systematically devaluing surgical care. Furthermore, in the past, when office visit code values increased, CMS also increased the post-operative E/M portion of the global surgery codes. The letter points out that to do otherwise will continue to:

• Disrupt the relativity in the fee schedule;
• Create specialty payment differentials; and
• Ignore recommendations endorsed by nearly all medical specialties.

The surgical community will continue to advocate for fair Medicare payment policies, leveraging the efforts of the Surgical Care Coalition — of which the CNS and the AANS are founding members — to demonstrate the value of surgical care and the need to increase global surgery payments.

### CMS Releases 2022 Medicare Physician Fee Schedule Proposed Rule

On July 13, 2021, CMS released the 2022 Medicare Physician Fee Schedule proposed rule. Overall, neurosurgery will receive a 3.2% payment cut in 2022. The cut stems from a lower conversion factor — from $34.89 in 2021 to $33.58 in 2022 — primarily due to the discontinuation of the 3.75% payment increase included in the Consolidated Appropriations Act, 2021. With the 2% Medicare sequester set to resume next year and additional Medicare payment cuts of up to 4% possible under pay-as-you-go rules to pay for the American Rescue Plan, providers could be facing up to 9% in payment cuts next year unless Congress intervenes.

In addition, CMS rejected the American Medical Association/ Specialty Society RVS Update Committee (RUC) recommended work relative values (wRVUs) for new laser interstitial thermal therapy (LITT) codes and the new arthrodesis decompression add-on codes to report decompression when performed in conjunction with posterior interbody arthrodesis at the same interspace (Table 1).

Finally, once again, CMS proposes to delay the effective date for the penalty phase of the Medicare AUC Program to either Jan. 1, 2023, or the first January following the end of the COVID-19 PHE, whichever is later.

### Medicare Releases 2022 Hospital OPPS/ASC Proposed Rule

On July 19, CMS released the 2022 Hospital Outpatient Prospective Payment System (OPPS) and Ambulatory Surgical Center (ASC) Payment proposed rule. The agency plans to increase hospital outpatient and ACS payment rates by 2.3%. Hospitals and ASCs that fail to meet their quality reporting program requirements would also be subject to a 2.0% reduction in the update. Also, CMS proposes to halt the elimination of the Inpatient Only (IPO) list. In 2020, there were 1,740 services on the IPO list. In 2021, CMS initiated a three-year transition to eliminate the IPO list, beginning with 298 mostly musculoskeletal-related services. If CMS finalizes this policy, these 298 services will be added back to the IPO list in 2022. In addition, CMS proposes to re-adopt the ASC Covered Procedures List (CPL) criteria in effect in 2020 and changed last year. The agency would also remove 258 of the 267 procedures added to the ASC CPL in 2021.

The reversals are in keeping with previous CNS and the AANS comments where we emphasized that the site of service should be determined by the surgeon and patient, not CMS. In last year’s comment letter, the neurosurgical groups raised patient safety concerns and worried that CMS would make it difficult to access the inpatient setting when necessary.

### Table 1

<table>
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<tr>
<th>CPT Code</th>
<th>Descriptor</th>
<th>RUC-Passed wRVU</th>
<th>CMS Proposed wRVU</th>
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<tr>
<td>617X1</td>
<td>Laser interstitial thermal therapy (LITT) of lesion, intracranial, including burr hole(s), with magnetic resonance imaging guidance, when performed; single trajectory for 1 simple lesion</td>
<td>20.00</td>
<td>19.06</td>
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<tr>
<td>617X2</td>
<td>Laser interstitial thermal therapy (LITT) of lesion, intracranial, including burr hole(s), with magnetic resonance imaging guidance, when performed; multiple trajectories for multiple or complex lesion(s)</td>
<td>24.00</td>
<td>22.67</td>
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<td>616X1</td>
<td>Laminectomy, facetectomy, or foraminotomy (unilateral or bilateral with decompression of spinal cord, cauda equina and/or nerve root[s] [e.g., spinal or lateral recess stenosis], during posterior interbody arthrodesis, lumbar; each additional segment</td>
<td>4.44</td>
<td>2.31</td>
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<tr>
<td>616XX</td>
<td>Laminectomy, facetectomy, or foraminotomy (unilateral or bilateral with decompression of spinal cord, cauda equina and/or nerve root[s] [e.g., spinal or lateral recess stenosis], during posterior interbody arthrodesis, lumbar; single vertebral segment</td>
<td>5.55</td>
<td>3.08</td>
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Mechanical Thrombectomy of the Anterior Cerebral Artery

A 45-year-old man with no significant past medical history presented with sudden-onset loss of movement in both his legs. On physical examination, he was fully oriented with normal upper extremity strength, but he had no movement in his lower extremities. CT perfusion demonstrated increased time to peak as well as salvageable penumbra in bilateral paramedian cortices (Figure 1). Angiography demonstrated an occlusion of the A2 segment of the left anterior cerebral artery (Figure 2A). Emergent mechanical thrombectomy was performed using aspiration technique (.045in.) inner diameter catheter). TICI 3 recanalization was achieved after the first pass. Post-procedure three-dimensional angiography demonstrated a variant of the anterior cerebral artery that supplied the paramedian cortex of both hemispheres (Figure 3). The right anterior cerebral artery ended in the orbitofrontal artery (Figure 2B). At one month followup, the patient was ambulatory with full strength in his lower extremities. Mechanical thrombectomy for primary occlusion of the anterior cerebral artery is rare and comprises less than 5% of all thrombectomy cases.

Submitted by: Rimal Dossani MD, Constantine Plakas MD
Lee Physician Group Neurosurgery, Fort Myers Fl.

Figure 1: Preoperative CT perfusion demonstrated increased time to peak and salvageable penumbra in bilateral paramedian cortices.

Figure 2: Angiography demonstrated an occlusion of the A2 segment of the left anterior cerebral artery (red arrow, A). The right anterior cerebral artery ended in the orbitofrontal artery (red arrow, B).

Figure 3: Three-dimensional angiogram demonstrated variant configuration of the left anterior cerebral artery as it supplied the paramedian cortex of both hemispheres.
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