NPA 2021 Update

In 2020, the NeuroPoint Alliance (NPA) completed an extensive strategic planning process and began implementing the new plan. One of the first steps in this process was establishing a provisional Board of Directors to set up the new governance structure and help set and implement NPA’s strategic priorities. The provisional Board of Directors slate has been approved and can be found on www.neuropoint.org/about-us/governance.

The NPA also hired a new Executive Director and VP of Registries and Data Science for the AANS, Stefan Rykowski.

- He brings over 15 years of working with data-driven products and programs and more than eight years managing health care data programs, processes and clinical registries.
- Mr. Rykowski managed large scale clinical data and quality programs, working with an array of stakeholders including government agencies such as the Defense Health Agency and Centers for Medicare and Medicaid Services, the American Association of Cardiology and the American Diabetes Association. He has also worked with industry and technology partners like AstraZeneca, Boston Scientific and FIGmd.

The NPA is excited to have his technical expertise and experience to help implement the new strategy and grow operations.

Look to future issues of NPA Newsline for the latest on registry programs, opportunities to participate or collaborate as well as

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The NPA is excited to announce the launch of the highly anticipated QOD Tumor Registry. Initially developed by the AANS/CNS Section on Tumors and the Quality Outcomes Database (QOD) Scientific Committee, the tumor registry first opened to seven pilot centers in February 2019. The registry completed an 18-month pilot period in July 2020 and was revised following pilot center feedback. The registry follows patients receiving surgery for intracranial metastases, primary meningeal, high-grade/malignant, low-grade/benign, pituitary and other intracranial tumors. Patient demographics, ICD-10 and CPT codes, comorbidities, hospital stay, 30-day readmission rates, post-operative complications and recurrent surgery are collected in the registry along with patient-reported outcomes measuring cognition impairment, physical function, QALY and cognitive function after surgery.

The QOD Tumor Registry is housed on the Research Electronic Data Capture (REDCap®) platform. Mayo Clinic serves as the coordinating center for the QOD Tumor Registry (www.mayoclinic.org/neurosurgery).

To learn more about and participate in the QOD Tumor Registry, contact the NPA at info@neuropoint.org or visit www.neuropoint.org.

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interest pieces that spotlight leadership and projects that demonstrate NPA efforts to advance the science and quality of neurosurgical care. If you would like further information about the NPA or would like to share information with the community, contact the NPA at info@neuropoint.org or visit www.neuropoint.org.

If you have an idea for a new project, submit your proposal at www.neuropoint.org/projects/propose-a-project/.
The American Spine Registry Closes its First Year

In 2020, the American Spine Registry (ASR), a collaboration between the American Association of Neurological Surgeons (AANS) and the American Academy of Orthopaedic Surgeons (AAOS), launched to leverage the capabilities of both organizations on a common platform. The registry is governed by equal representation between the AANS and AAOS. Registry participation includes sites throughout North America, creating an unparalleled resource to improve spine care outcomes through data.

The registry has grown quickly, with more than 150 participating sites and multiple opportunities for data re-use. Participants have access to analytics resources, including reports and dashboards, to analyze data and help inform their spine practice with national benchmarks. ASR participation also satisfies Part IV of the American Board of Neurological Surgery Continuous Certification and can be used for other quality initiatives. For more information, visit www.americanspineregistry.org.

NVQI-QOD: Neurovascular Registry Reaches its First Year

January marks the first anniversary of the NVQI-QOD neurovascular registry. A collaborative effort between the NPA and the Society of NeuroInterventional Surgery (SNIS), the NVQI-QOD combines the SNIS’ NeuroVascular Quality Initiative (NVQI) registry with the NPA’s Quality Outcomes Database Neurovascular registry (QOD-NV) into one unified program focused on quality improvement. Thirty-four centers and 135 physicians across the country are now participating in the NVQI-QOD 21 states, with more than 10,000 procedures captured.

NVQI-QOD offers modules for acute ischemic stroke, cerebral aneurysm and cerebral arteriovenous malformation. NVQI-QOD captures 100% of procedures, including demographic, procedure and post-op data, to provide comprehensive outcome analysis and inform performance improvement, with long-term outcomes one year or longer also collected.

The registry is governed by the SNIS Patient Safety Organization and takes direction from the NVQI-QOD Governing Council, which is comprised of representatives from both the NPA and SNIS. The registry is housed on the M2S® PATHWAYS® web-based clinical platform, which includes analytics, reporting and support for the registry.

To learn more about the NVQI-QOD and to participate, contact info@neuropoint.org or visit www.nvqi-qod.org.
A National Quality Improvement Registry for Cranial SRS Treatments

In 2015, the AANS established the Stereotactic Radiosurgery (SRS) Registry in concert with the American Society for Radiation Oncology (ASTRO) to collect data on the radiosurgical treatment of brain metastases, primary malignant and benign brain tumors as well as arteriovenous malformations. During the initial three-year phase of the program, the registry accrued longitudinal treatment and outcomes for more than 3,000 patients from device-specific data extraction platforms at over 20 high-volume centers across the United States. The SRS has evolved into a partnership with Brainlab to use the Quentry for SRS® technology platform to streamline data collection, integrate workflows and enhance the analyses of information collected throughout the sequence of patients’ SRS treatments. To date, the SRS Registry has accrued data on more than 4,000 patients, capturing patient characteristics, treatment patterns and outcomes.

Brainlab has begun migrating sites to Quentry Cloud Service® and looks forward to working with sites to migrate to this point-of-care application-based platform through 2021 to increase data access, reduce data input burdens and integrate directly into participant workflows. Patient baseline and follow-up information includes lesion volume changes and recurrence, lesion response to treatment, neurological examination findings, patient quality of life, adverse events and survival.

The NPA invites inquiries from centers interested in a structured quality improvement program for SRS that can meet the minimum 40-patient enrollment in twelve months and comprehensive follow-up requirements. The registry has been designated a non-research clinical improvement effort by the Western Institutional Review Board (WIRB). The registry receives in-kind and financial support from Brainlab and the registry software is provided to sites at no charge. Sites are eligible to receive grant support for data collection and follow-up efforts.

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Spine Collaboration for Outcomes Research (Spine CORe) Updates

Initially named the Spondy Study Research Group, the Spine Collaboration for Outcomes Research (Spine CORe) was formed in 2016 by physician champions in several QOD spine centers across the country. The research group’s first study, “Effectiveness of Grade I Spondylolisthesis” (Spondy Study), took a cohort of 12 QOD participating sites and examined respective surgical approach in treating patients with spondylolisthesis. QOD data from July 1, 2014, to June 30, 2016, were analyzed, and the two-year manuscript will be published in the JNS Spine in early 2021. Over the past year, abstracts and 15-20 oral and poster presentations stemming from this Spondy Study have been accepted nationally and internationally, including two podium presentations at large neurosurgical national meetings. The study was supported by grants from Medtronic and DePuy.

In 2019, the research group was renamed the Spine CORe. It kicked off two new studies in 2020, which take a look at cervical spondylotic myelopathy (CSM) data and high-grade spondylolisthesis (grade 2/3 spondy) data. The Spine CORe is also exploring funding opportunities for these studies.

To learn more about the Spine CORe studies, propose a new study or to get involved, contact the NPA at info@neuropoint.org.

2020 Highlights

- Abstracts and 15-20 oral and poster presentations stemming from the Spondy Study have been accepted nationally and internationally
- Spine CORe kicked off two new studies that take a look at cervical spondylotic myelopathy (CSM) data and high-grade spondylolisthesis (grade 2/3 spondy) data
Registry for the Advancement of Deep Brain Stimulation Therapy in Parkinson’s Disease (RAD-PD) Reopens to New Patients

The Registry for the Advancement of Deep Brain Stimulation Therapy in Parkinson’s Disease (RAD-PD) is a quality improvement effort focused on deep brain stimulation therapy and outcomes for Parkinson’s disease (PD) patients. The registry partners are the Parkinson Study Group, the NPA and the financial sponsor is the Michael J. Fox Foundation. The NPA serves as the registry and technical platform manager. The RAD-PD patient registry originally launched in the fall of 2018 and the first registry patient was enrolled in March 2019. In January 2020, the registry switched its data management platform to the Research Electronic Data Capture (REDCap®) platform. The registry relaunched on the REDCap® platform in September 2020 and the first patient was enrolled on the new system in November 2020. The registry has 20 participating centers and has enrolled approximately 50 patients.

In 2021, the NPA will look to continue its partnerships and raise the bar on registry goals. Minimum patient enrollment goals should grow to include more than 316 patients. RAD-PD priorities for the year include working with registry partners to incorporate image data capture and analysis.

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