

# CEREBRAL PALSY RESEARCH NETWORK (CPRN) STRATEGIC PLAN 2016-2020

**MISSION:** The mission of the Cerebral Palsy Research Network (CPRN) is to improve outcomes that people with cerebral palsy value most through high quality clinical research and quality initiatives.

**VISION:** The Cerebral Palsy Research Network vision is to translate the knowledge from research such that every clinician treating persons with CP is offering the best, most current treatments available. Every center with a CP clinic will include its patients’ treatment data in the CPRN registry. This registry, combined with a patient-powered registry and broad participation from people with cerebral palsy, will enable clinician-researchers to find practice variation and create quality initiatives to improve outcomes for all patients with CP, regardless of where they are treated.

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|-------------------------|-------------------------|---------------------------------|---------------------|
| <b>VALUES:</b>          | ➤ <b>Collaboration</b>  | ➤ <b>Openness</b>               | ➤ <b>Quality</b>    |
| ➤ <b>Impact</b>         | ➤ <b>Evidence-based</b> | ➤ <b>Transparency</b>           | ➤ <b>Efficiency</b> |
| ➤ <b>Sustainability</b> | ➤ <b>Integrity</b>      | ➤ <b>Family/Person Centered</b> |                     |

**5-YEAR STRATEGIC INITIATIVES:** The initiatives listed below are aimed at achieving our mission and vision. A description of each initiative and related goals and measures for success can be found on the following pages.

*Initiative 1: Foster and conduct high-quality, multi-center multi-discipline quality initiatives and clinical research on cerebral palsy.*

- **Goal 1:** Attract 10 centers and 20 clinical researchers with track records of excellence in clinical research.
- **Goal 2:** Establish clinical and patient reported registries.
- **Goal 3:** Launch two or three peer-reviewed, publicly funded clinical studies focused on the most pressing clinical issues and one to two quality initiatives.
- **Goal 4:** Publish 10 articles in high quality journals.

*Initiative 2: Sustain a world-class multi-center and patient-centered clinical research organization.*

- **Goal 5:** Create the fiscal infrastructure to generate public and private funding for studies.
- **Goal 6:** Create operational framework and establish relationships with key organizations to help direct and support the studies
- **Goal 7:** Create appropriate governance structures to oversee the work of CPRN participants
- **Goal 8:** Attract sufficient public and private funding to achieve our study goals.

*Initiative 3: Translate knowledge broadly.*

- **Goal 9:** Decrease practice variation among member institutions of CPRN.
- **Goal 10:** Make knowledge available to consumers and clinicians via flexible formats and accessible platforms
- **Goal 11:** Increase the percentage patients receiving evidence-based treatments with in our network.

**Initiative 1: Stimulate and conduct high-quality, multi-center, multi-discipline quality initiatives and clinical research for cerebral palsy.**

*Rationale:* Cerebral palsy, while the most common motor condition in children, is neither prevalent enough for single center research nor narrow enough in etiology or manifestation for single discipline research to yield field-changing results. Multi-center, multi-discipline research is necessary to derive meaningful outcomes that can be targeted for appropriate populations and etiologies. The synergy between quality improvement initiatives and comparative effectiveness research organizations has been demonstrated by recent efforts of organizations like Improve Care Now and the Hydrocephalus Clinical Research Network. And the integration of patient reported outcome registries has altered the landscape for how treatments and outcomes can rapidly improve in numerous diseases including Irritable Bowel Syndrome, Oncology and Hydrocephalus.

**Goal 1: Attract ten institutions and researchers with a track record of excellence and commit to clinical research, quality improvement and collaboration.**

- CPRN's goal is to attract the best and brightest clinicians and researchers committed to studying this condition and dedicated to making a dramatic impact on improving care and treatment for people living with cerebral palsy. We need clinicians and researchers want to devote time and energy into establishing a high quality evidence base for treatments that result in the best outcomes.
- Metrics for measuring success: *We'll know we've been successful if...*
  - we've established and documented criteria for individual and center inclusion in the network by June 2016. Preliminary criteria for inaugural participants will be a track record of research and collaboration within an institution treating a high-volume of CP cases and the availability of time and interest by a primary investigator for studying cerebral palsy. Commitment Information Technology administrators as well as alternate PI and practice partners of the PI to participate in the studies is also important.
  - we have signed on ten charter member institutions and primary investigators and related study support staff by April 2016.

**Goal 2: Establish clinical and patient reported registries to enable not only high quality research but also provide a basis for finding practice variation that supports the creation of quality improvement initiatives.**

- CPRN's clinical registry will characterize the patient population sufficiently to enable hypothesis generation and an accurate estimate of patient cohorts and study recruitment capability across the network. That same registry will capture practice variation that when combined with patient reported outcomes will support the establishment and tracking of quality improvement initiatives that will fundamentally alter the treatment standards for people with cerebral palsy.
- Metrics for measuring success: *We'll know we've been successful if...*
  - CPRN sites standardize the data collected on CP patients.
  - The CPRN registry provides significant quantities of preliminary data that is used to support multiple grant applications.
  - CPRN studies are able to predict and accrue eligible patients with a high rate of speed and accuracy.
  - CPRN develops multiple quality improvement protocols and patient report outcomes reflect improvement.

- Patient reported outcomes are collected and reviewed by clinicians for more than 50% of clinic visits at CPRN sites.
- CPRN expands membership to include data only, quality improvement sites for its registry.
- Most major CP centers, defined as sites with an annual caseload of 500 clinic visits and/or surgical events, having joined CPRN, will have implemented CPRN quality improvement protocols and other improvements as dictated by study findings.

**Goal 3: Launch two to three clinical studies focused on the most pressing and widespread clinical research questions and one to two quality initiatives all based on input from clinicians and people with CP.**

- CPRN's goal is attract funding and execute multiple clinical studies that address major issues facing families and patients with diagnoses of cerebral palsy. Examples of key issues are: comparative effectiveness of lower extremity surgical interventions...,
- Metrics for measuring success: *We'll know we've been successful if...*
  - we have created a method for identifying the major clinical research gaps that are pressing and widespread for those enduring cerebral palsy by 2016.
  - our charter members and patient advocates can, by December 2016, agree on a preliminary research agenda.
  - Institutional Review Boards/Research Ethics Boards approve our research methods for human subjects by July of 2016.
  - our research teams are quickly accruing appropriate study participants within protocol guidelines. (Note: each study will have a relevant data collection timeline against which to measure success -need to define when studies are set).
  - our findings are statistically sound and significant and indicate a path toward improvements in cerebral palsy patient care.

**Goal 4: Publish 10 journal papers.**

- CPRN's goal is to inform the medical, patient and stakeholder communities, and, through that channel, inform the broader public, about the importance of our findings. The current paradigm for doing this is to publish in peer-reviewed journals and to have those stories be covered by mainstream press outlets as well as coverage in the social media outlets of the leading patient advocacy organizations.
- Metrics for measuring success: *We'll know we've been successful if...*
  - our papers are selected for publication and highlighted in major journals.
  - our research attracts mainstream press and social media attention

**Initiative 2: Create a world-class multi-center and patient-centered clinical research organization.**

*Rationale: The success of model multi-center clinical networks like Children's Oncology Group, Hydrocephalus Clinical Research Network and Improve Care Now rests on a sound foundation of organizational excellence and patient involvement. In order for researchers to focus on their work, administrators need to provide them the infrastructure to accomplish the complex tasks of coordinating multi-center clinical trials and quality improvement studies. This infrastructure is intended to allow the network to grow rapidly while accommodating more studies and participants and still being responsive to patient needs and outside parties. Making sure these details are attended to in a professional, timely, and prudent manner is the rationale behind this initiative.*

**Goal 5: Create the fiscal infrastructure to generate public and private funding for the registry and multiple quality improvement and research studies.**

- CPRN's goal is support our investigators to competitively pursue funding for the studies that are so important to our mission. Having a nonprofit funding vehicle with minimal overhead, and mechanisms for properly managing tax deductible philanthropy, along with institutional and government income, will be imperative. CPRN values quality and transparency and our fiscal efforts should be both professional and open to scrutiny.
- Metrics for measuring success: *We'll know we've been successful if...*
  - we've secured the founding philanthropists' resources for launching the network **by June 2015**.
  - we've established an operating budget for income and expenses **by June 2016**, developed processes for annual budgeting, and monitored financial reports quarterly.
  - we've established a fiscal agency agreement with a host nonprofit **by June 2015**.
  - we've established a written financial controls policy **by June 2016** and reviewed yearly.
  - we've established written methods for promptly processing personnel and vendor payments and for handling income.

**Goal 6: Create the operational framework and establish relationships with key organizations to help direct and support the studies.**

- CPRN's goal is to provide the most professional and responsive operational support to study members with a staffing and support footprint that is prudent, efficient, and reflective of excellent stewardship of the resources entrusted to us. Where outsiders are more cost-efficient and effective at delivering a service, CPRN will contract out the work, assuming it does not compromise study integrity or patient privacy. Where partnerships and collaborations could successfully deliver the necessary service, those will also be examined and considered before building out our own infrastructure.
- Metrics for measuring success: *We'll know we've been successful if...*
  - we have created group collaboration tools, resources, and events (Intranet, conference calling, meeting facilities, and working processes) that are well adopted, understood, and that help all participants feel connected, helpful, and productive measure by participation and follow-up as of **June 2016**.
  - we have provided clear project management direction and communication through the use of collaborative tools and communications demonstrated by the achievement of milestones and deliverables by **December 2016**.
  - we have provided IT infrastructure and support for study data collection and data management demonstrated by the launch of the registry at multiple sites and the successful transfer, transform and load of data into the CPRN registry by **September 2016**.
  - we have authored and provided written administrative materials to all relevant participants including: study manuals, IRB submission and renewal paperwork, and CPRN constitution and administrative manuals by **December 2016**.
  - we are rated as very responsive and professional by our medical researchers in half-annual surveys.

**Goal 7: Create appropriate governance structures to oversee the work of CPRN participants and represent the needs of the CP community.**

- CPRN's goal is to have the results of our work stand up to professional scrutiny and the needs of the cerebral palsy community. There can be no question about the ethics and integrity of our work. Appropriate governance oversight will ensure that all decisions are fair and that the work is conducted with utmost professionalism.
- Metrics for measuring success: *We'll know we've been successful if...*
  - we've defined the requirements, terms, responsibilities and process for selecting executive advisory board members **by January 2017** and recruited the charter members **by June 2016**.
  - CPRN participants feel there are fair and just decisions being made concerning who does or doesn't participate in the CPRN and that the process for making these decisions is documented and transparent to all interested parties.
  - we have created the appropriate managerial oversight to make sure goals/metrics/milestones are being monitored and communicated effectively back to the group.
  - our studies are considered of high-quality by peers in the medical research profession.
  - patients, caregivers and other stakeholders are consistently involved in the planning and execution of our research.
  - our studies are considered pressing and important by the cerebral palsy community.

**Goal 8: Attract sufficient public and private funding from institutional and government support to achieve our study goals described above.**

- CPRN's goal is to have the necessary resources to do true collaborative, and field-changing, clinical research. An initial 5-year total outlay of approximately \$500,000 to support the development and maintenance of our Data Coordinating Center and registry database has already been committed. CPRN investigators will need to seek public and private grant funding to support the studies informed by the CPRN registry.
- Metrics for measuring success: *We'll know we've been successful if...*
  - we've attracted additional grant funding for at least **four** studies and/or quality improvement protocols totaling for an annual research/QI investment of \$1,000,000.
  - we've established a business model for our QI initiatives to sustain those efforts and the infrastructure and staffing to execute them.
  - our QI results and business model enable broad participation by centers that treat people with cerebral palsy by **2020**.
  - our funding partners feel very satisfied with the progress and impact of our research and are properly thanked for their involvement and support.
  - the patients treated at our centers are experience improved outcomes as measured by our patient reported outcome metrics.

**Initiative 3: Create a lasting impact through broad participation and adoption of key findings through a variety of knowledge translation mechanisms.**

*Rationale: Our work will have been in vain if it did not impact treatment improvements and outcomes for people with cerebral palsy. Because we can only directly influence the professionals in the CPRN, and the patients they touch, our goal is to scale our quality improvement efforts as broadly as is practical. This expansion and inclusion of centers will maximize the impact of our work. We will implement knowledge translation mechanisms that maximize the improvements in care as broadly as is possible.*

**Goal 9: Decrease practice variation among members of CPRN.**

- CPRN's quality improvement methods will seek to improve outcomes meaningful to patients through reducing practice variation. Our registry will capture many of the degrees of variation across CPRN centers. Our QI methodologies should have the effect of reducing that variation in practice.
- Metrics for measuring success. *We'll know we've been successful if...*
  - we establish quantifiable differences across the treatment of patients at CPRN sites and target some of that variation for QI initiatives.
  - **by 2020**, the quantifiable differences in practice variation have reduced and patient centric outcomes have improved.

**Goal 10: Make knowledge available to consumers and clinicians via flexible formats and accessible platforms**

- One of CPRN's goals is to not only reach beyond CPRN centers but also inform patients and families about best practices in the treatment of CP. We will need to collaborate with the American Academy of Cerebral Palsy and Developmental Medicine and other professional societies to maximize the distribution and training of our findings. And we will need to establish direct and indirect connections to patients and families to disseminate our findings. We will leverage different training methodologies and media to improve the uptake of our work.
- Metrics for measuring success. *We'll know we've been successful if...*
  - we have established collaborations with AACPD, POSNA, APTA, AANS, AAP, AAPMR, AAN and other professional societies to leverage our work to improve the state of care and outcomes in CP.
  - we have formed partnerships with leading patient advocacy organizations and hospitals to disseminate our findings to their constituents and patient populations.
  - we have shared our results in a broad variety of formats (publications, video, CMEs, web, etc.) to enable the broadest adoption of our findings.

**Goal 11: Increase the percentage patients receiving evidence based treatments with in our network.**

- CPRN's goal is better treatment and better clinical and patient reported outcomes for people with cerebral palsy based on clinically proven treatments. We will only be successful if the mix of care for patients shifts toward treatments with the strongest evidence base.
- Metrics for measuring success. *We'll know we've been successful if...*
  - we've published evidence-based best-practice guidelines for all medical professionals that encounter patients with cerebral palsy in major journals by **2020**.
  - treatments tracked in the registry will skew toward "green light" interventions.