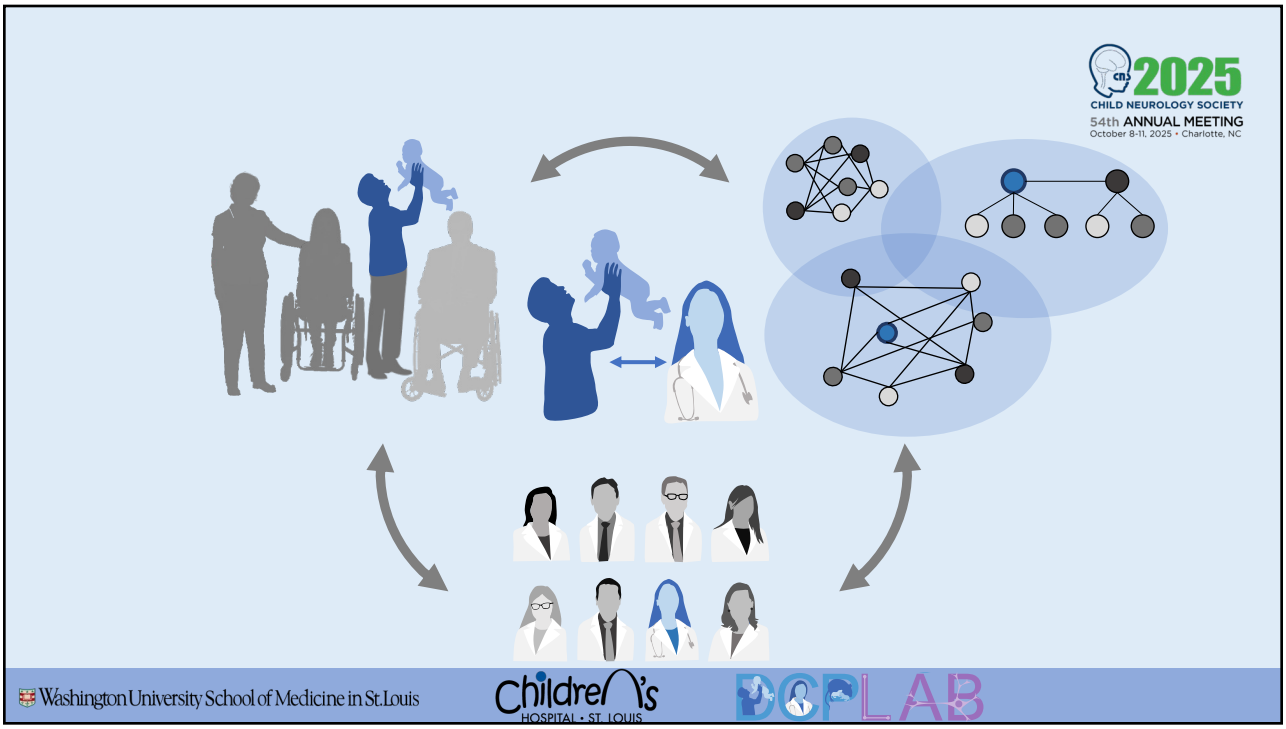
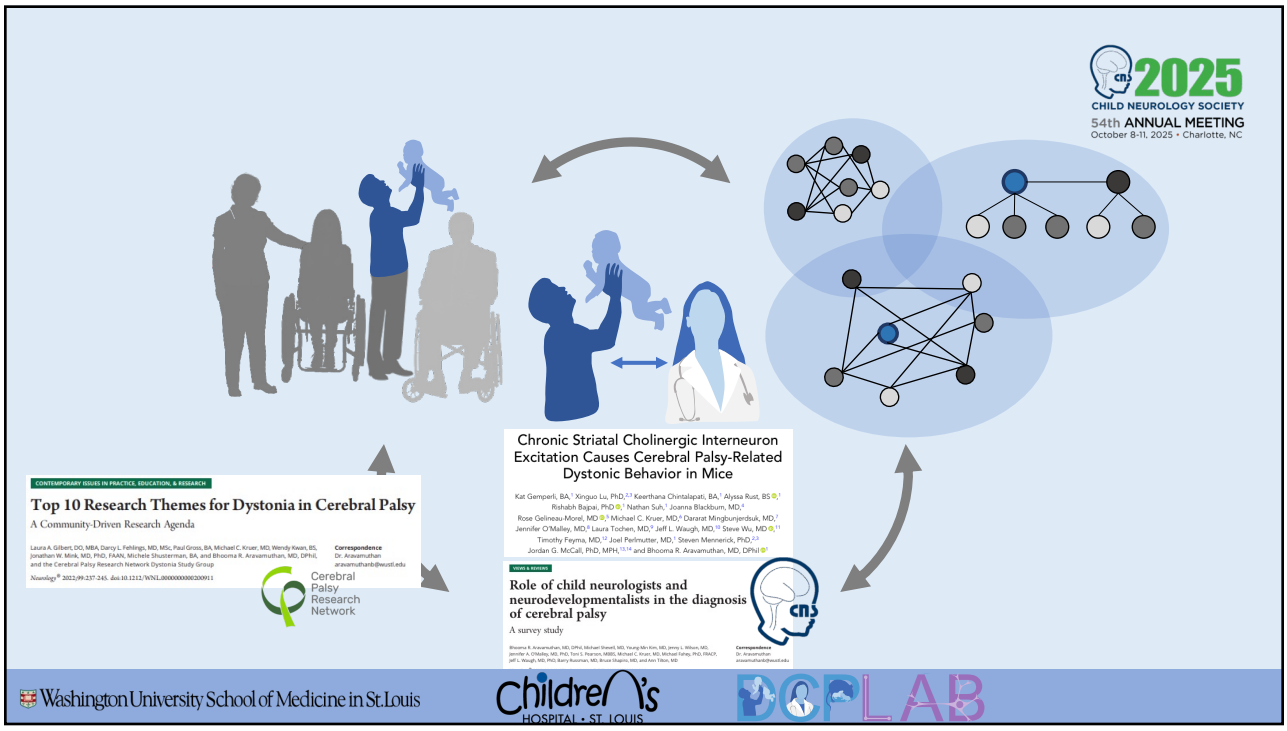
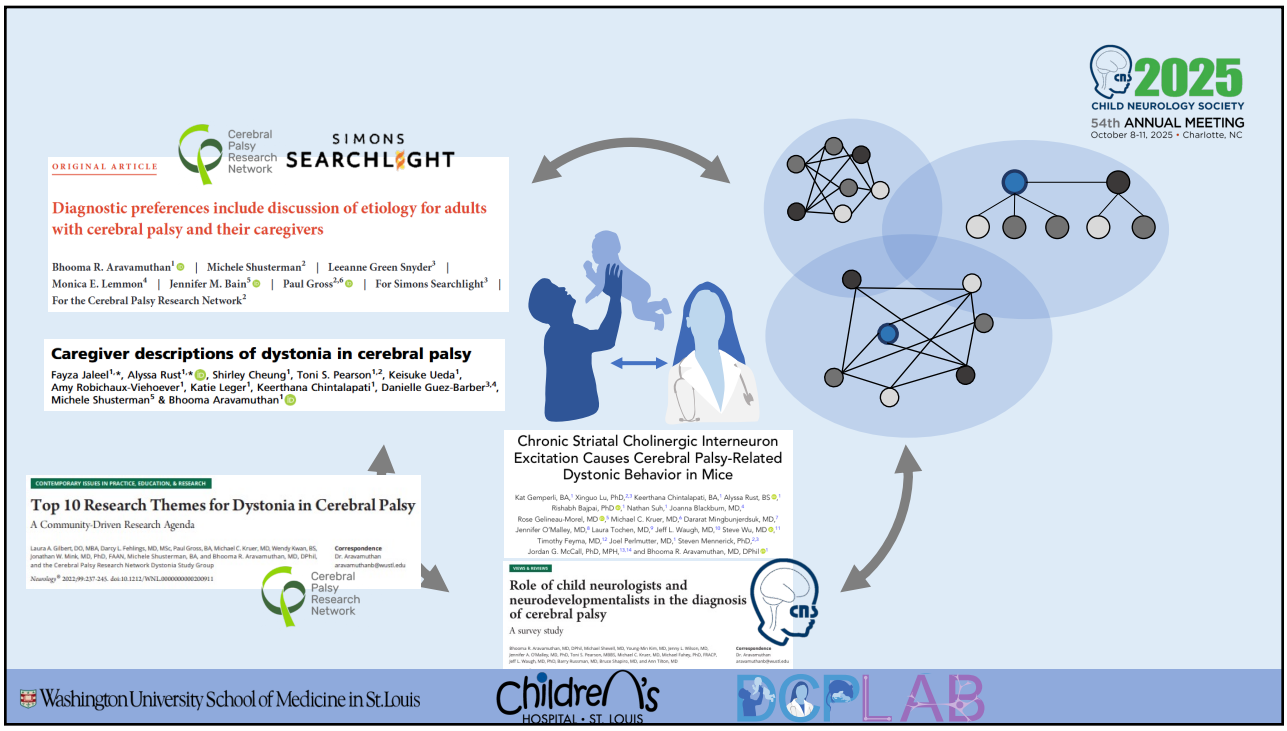
Fostering research collaboration

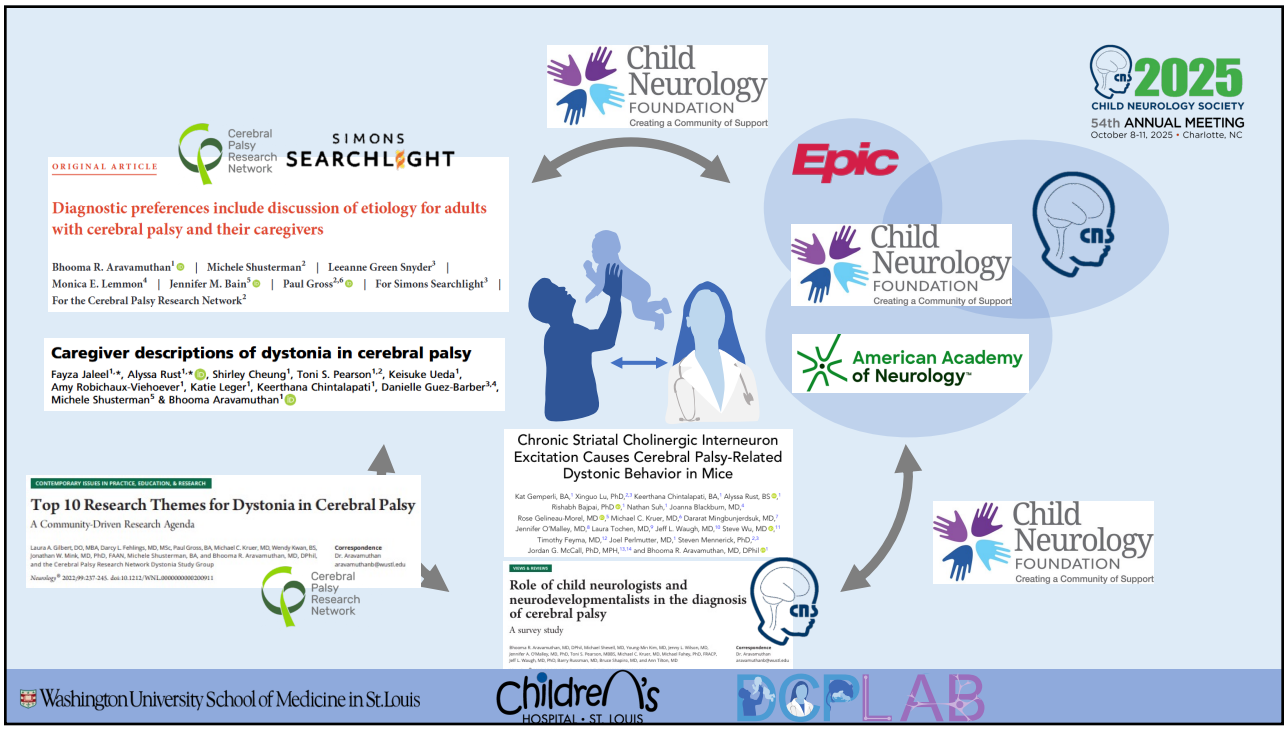
2025 CHILD NEUROLOGY SOCIETY 54th ANNUAL MEETING October 8-11, 2025 • Charlotte, NC

Bhooma Aravamuthan MD DPhil FAAN FCNS
Director, Cerebral Palsy and Mobility Center
Assistant Professor of Neurology and Pediatrics
Washington University in St. Louis and St. Louis Children's Hospital




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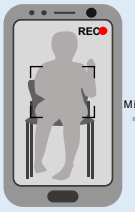

Child Neurology FOUNDATION
Creating a Community of Support
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Epic
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American Academy of Neurology
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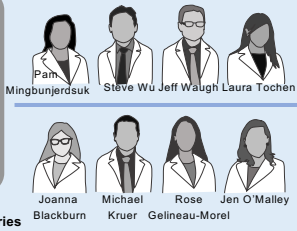
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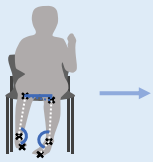


Create video registries of people with cerebral palsy



Physicians assess videos for dystonia severity and describe what they see





Quantify physician-cited features to build AI-driven dystonia diagnostic models



DxTonia:
Open-source software to identify leg dystonia in videos of people with CP



Rishabh Bajpai

Gillette Children's Specialty Healthcare

Children's Hospital • St. Louis

300+ videos…and they keep agreeing to review more

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Tom Novacheck

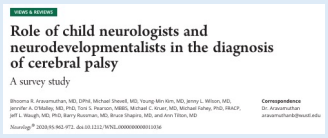
Gillette Children's Specialty Healthcare

Cerebral Palsy Research Network



- Follow up on people's interest
  - Follow through
- Reach out to people you have never met
  - Worst case – they say no / don't respond
- Minimize the stick, maximize the carrot
  - Set clear expectations re: time commitment and recognition of contributions IN WRITING, AT THE BEGINNING
- Open communication
- Celebrate hard work

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Role of child neurologists and neurodevelopmentalists in the diagnosis of cerebral palsy

A survey study

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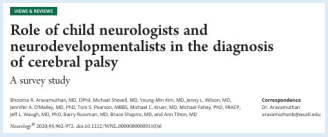
65%

Of surveyed child neurologists and neurodevelopmentalists think they should ALWAYS be involved in CP diagnosis

Table 6 Respondent views on the overlap between skills important for cerebral palsy care and the expertise of child neurologists and neurodevelopmentalists

	Median perceived importance rating for diagnosis or management	Median perceived CN/NDD expertise rating
Queried CP care skills	1 = not important, 3 = valuable, 5 = critical	1 = no expertise, 3 = competent, 5 = uniquely expert
Differentiation between different CP motor abnormalities (e.g., spasticity vs dystonia)	4.5	5

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- Level up
- "Make it science"
- Shared leadership model
- Collaborate with people you like


Young-Min Kim

AACPDM


Michael Shevell


Barry Russman


Roger Larson




Jen O'Malley


Jenny Wilson


Rose Gelineau-Morel

SIGnature Libraries: A roadmap for the formation of special interest group libraries

Young-Min Kim, Eric M. Chin, Michael Fahey, Rose Gelineau-Morel, Kate Himmelmann, Jennifer O'Malley, Maryam Oskoui, Bruce Shapiro, Michael Shevell, Jenny L. Wilson, Max Wiznitzer, the Child Neurology Society Cerebral Palsy Special Interest Group Consortium, Bhooma Aravamuthan

Cerebral Palsy in Child Neurology and Neurodevelopmental Disabilities Training: An Unmet Need

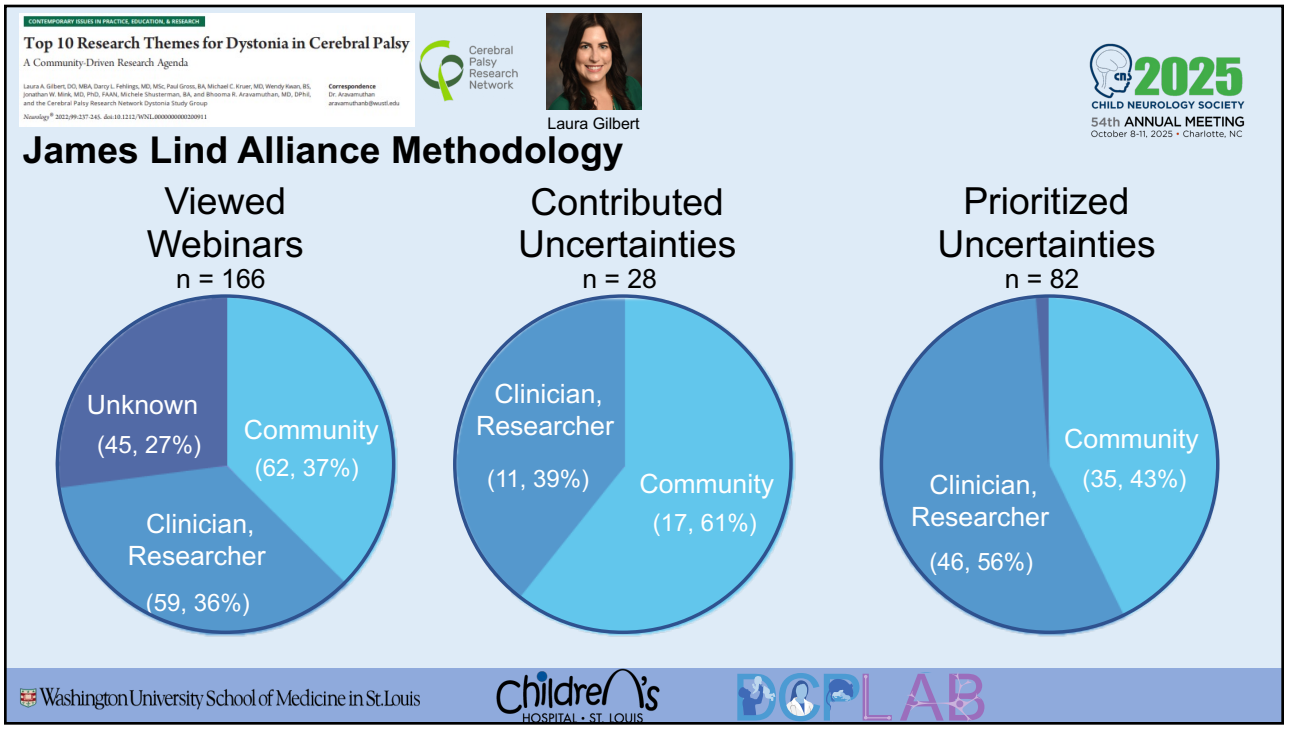
Jenny L. Wilson [1], Young-Min Kim [2], Jennifer A. O'Malley [3], Rose Gelineau-Morel [4], Laura Gilbert [5], Jennifer M. Bain [6], and Bhooma R. Aravamuthan [5]

The Role of Child Neurologists in the Management of Motor Disability in Cerebral Palsy: Establishing the Path Forward

Rose Gelineau-Morel, MD [a,*], Young-Min Kim, MD [b], Jennifer A. O'Malley, MD, PhD [c], Jenny L. Wilson, MD [d], Bhooma R. Aravamuthan, MD, DPhil [e]

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Laura Gilbert
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James Lind Alliance Methodology
Viewed Webinars
n = 166
Unknown (45, 27%)
Community (62, 37%)
Clinician, Researcher (59, 36%)
Contributed Uncertainties
n = 28
Clinician, Researcher (11, 39%)
Community (17, 61%)
Prioritized Uncertainties
n = 82
Community (35, 43%)
Clinician, Researcher (46, 56%)
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CONTEMPORARY ISSUES IN PRACTICE, EDUCATION, & RESEARCH

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Correspondence
Dr. Aravamuthan
aravamuthanb@wustl.edu

Neurology® 2022;99:237-245. doi:10.1212/WNL.0000000000200911

Cerebral Palsy Research Network


Laura Gilbert

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1. New treatments
2. Rehab approaches
3. Compare current treatments
4. Improve diagnosis and severity assessment
5. Effect of mixed tone
6. Treatment response prediction
7. Pathophysiology
8. Pain treatments
9. Natural history
10. Family awareness

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- Ask to join an existing collaboration

Cerebral Palsy Research Network


Paul Gross


Jon Mink


Darcy Fehlings


Michael Kruer

- Hand over


Laura Gilbert

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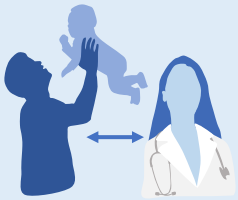
ORIGINAL ARTICLE

Diagnostic preferences include discussion of etiology for adults with cerebral palsy and their caregivers

Bhooma R. Aravamuthan[1] | Michele Shusterman[2] | Leeanne Green Snyder[3] | Monica E. Lemmon[4] | Jennifer M. Bain[5] | Paul Gross[2,6] | For Simons Searchlight[3] | For the Cerebral Palsy Research Network[2]

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197 people surveyed

Cerebral Palsy Research Network

Simons Searchlight Foundation

75% valued knowing the cause of their CP

48% had been told the cause of their CP by a medical practitioner

68% preferred carrying a CP diagnosis **together** with an etiologic diagnosis

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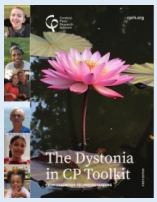
- Recruit targeted expertise

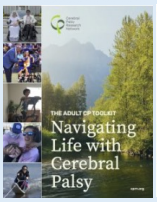
Cerebral Palsy Research Network | MyCP

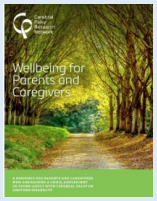


Michele Shusterman

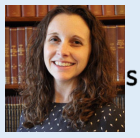






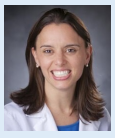


cprn.org/our-toolkits/



Jen Bain

SIMONS SEARCHLIGHT



Monica Lemmon

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Fayza Jaleel


Alyssa Rust

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1. When you try to move one part of your body, do you move another part of your body without meaning to?
2. During activities when someone handles a part of your body, do you move a different part of your body without meaning to?

YES to both?

92%

had dystonia

Cerebral Palsy Research Network

RESEARCH ARTICLE

Multicenter Improvement in Screening for Dystonia in Young People With Cerebral Palsy

Bhooma Rajagopalan Aravamuthan,[1] Emma J. Lott,[1] Esra Pehlivan,[1] Keerthana Chintalapati,[1] Deborah Grenard,[2] Desiree Roge,[3] Rose Gelineau-Morel,[4] Dante Kyle,[4] Christie Becu,[5] Michael C. Kruer,[5] Linn Katus,[6] Paul Gross,[7] and Amy Bailes,[8] for the Cerebral Palsy Research Network

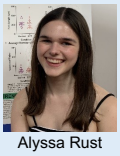
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Caregiver descriptions of dystonia in cerebral palsy

Fayza Jaleel[1,*], Alyssa Rust[1,*], Shirley Cheung[1], Toni S. Pearson[1,2], Keisuke Ueda[1], Amy Robichaux-Viehoever[1], Katie Leger[1], Keerthana Chintalapati[1], Danielle Guez-Barber[3,4], Michele Shusterman[5] & Bhooma Aravamuthan[1]


Fayza Jaleel

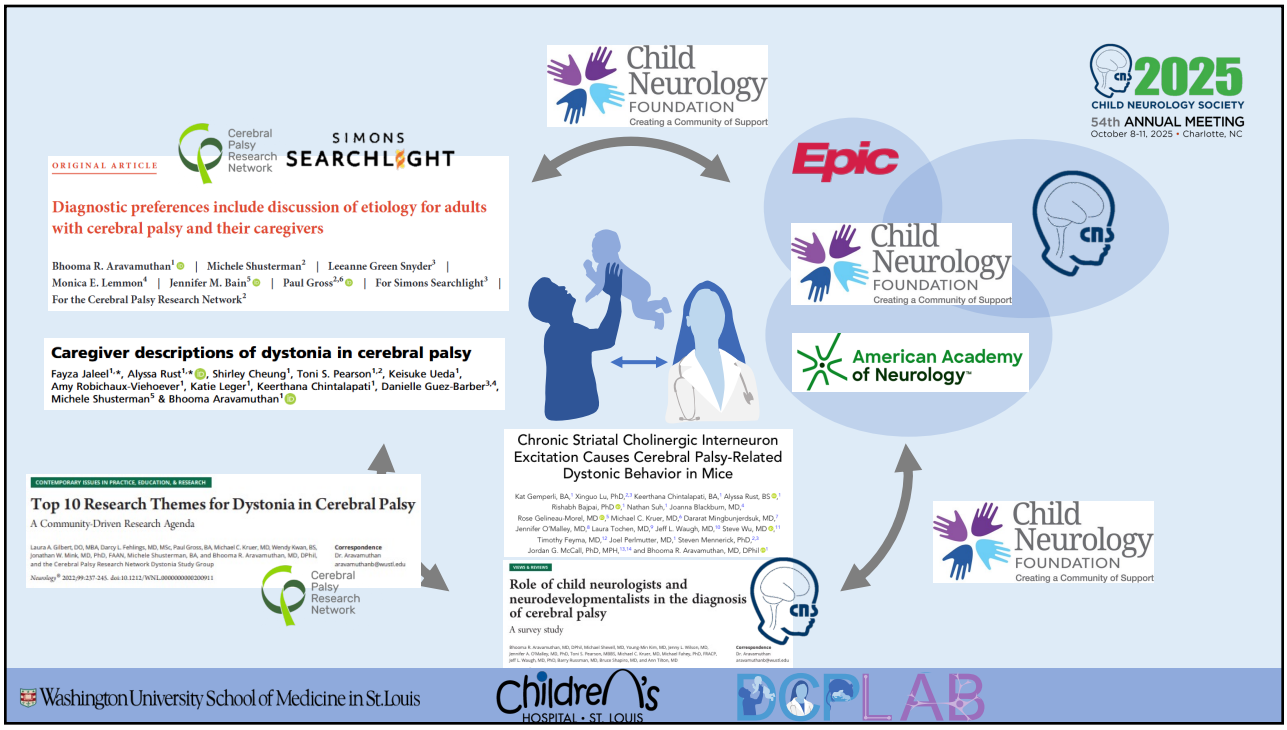

Alyssa Rust

CNS 2025 CHILD NEUROLOGY SOCIETY 54th ANNUAL MEETING October 8-11, 2025 • Charlotte, NC

- Passion and hard work >>> experience

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SIMONS SEARCHLIGHT
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Creating a Community of Support
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Collaborating on Transition of Care: Past & Present

Past Collaboration

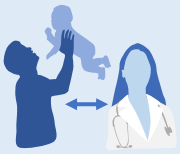
- Formed the **Transition Project Advisory Committee (TPAC)** to guide transition work
- Updated the **Transition of Care Toolkit** with inclusive principles and integrated it into Epic for direct provider use
- Partnered with clinicians to **develop a free CME course** and **lead four national workshops** reaching nearly 200 colleagues
- **Co-created a resource website** with videos tailored for clinicians, caregivers, and patients
- With clinician guidance, **distributed millions in grants** to improve pediatric transition efforts

Present & Future Collaboration

- Partnering with the **American Academy of Neurology (AAN)** to expand impact
- Establishing an **Executive Task Force** as the next phase of TPAC
- Conducting a **landscape analysis of adult models of care** to identify best practices
- **Gathering insights directly from patients and caregivers** to ensure recommendations reflect lived experience
- **Developing a recommended adult model of care** that is practical, evidence-based, and community-informed

Play the long game

From transition tools to future care models, CNF and clinicians continue building solutions together.

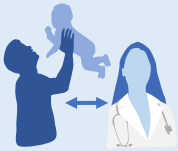


Collaboration tips

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- Follow up and follow through
- Reach out
  - Recruit targeted expertise
  - Ask to join an existing collaboration
- Minimize the stick, maximize the carrot
  - Set clear expectations IN WRITING, AT THE BEGINNING
- Open communication
- Celebrate hard work
- Level up / Hand over

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Collaboration tips

- "Make it science"
- Share leadership
- Play the long game
- Collaborate with people you like
  - Work with passionate people

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SIMONS SEARCHLIGHT | Epic | American Academy of Neurology | Child Neurology Foundation | Cerebral Palsy Research Network

Thank you!

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