Developing Team NEMO
Implementation of Early Detection of Cerebral Palsy at UCLA

UCLA Tarjan Center Distinguished Lecture Series
February 12, 2024

Sai Nandini Iyer, MD
UCLA Developmental Behavioral Pediatrics
Disclosure

• I have nothing to disclose
Background

• International guidelines for early detection and intervention for CP (Novak, 2017 and Morgan, 2021)
  • Diagnosis of CP prior to 2 years using a series of assessments and care pathways
  • “High-risk for CP” at 3-4 months, prior to confirmed diagnosis
  • Parent empowerment = proven and critical element of these guidelines
Background

• Translating the research evidence of guidelines into clinical practice → standard of care

• Knowledge-to-action cycle (Graham, 2006)
  • Details an effective approach, with stages and elements, in achieving sustainable transfer of research knowledge into clinical practice
Knowledge to Action Framework – CP Foundation

• Phase 1
  • Standardization of the neurological examination; routine use of the Hammersmith Infant Neurological Exam (HINE) in all NICU HRIF clinics at Nationwide Children’s Hospital (Maitre, 2016)

• Phase 2
  • Implementation of early detection guidelines at Nationwide Children’s Hospital HRIF (Byrne, 2017)

• Phase 3
  • Cycle 1: Multisite implementation and adoption of the guidelines across the CPF Early Detection Network of 5 US sites, including UCLA (Maitre, 2020)
Objective - UCLA site

• To implement the guidelines for early diagnosis and intervention for cerebral palsy in the UCLA NICU/HRIF clinic aiming to decrease the age of CP diagnosis to under 12 months
Methods

• Team NEMO (Neurodevelopmental and Early Movements Observation) was formed to facilitate the implementation

• Preparation phase – 3 months
  • Site visits
  • SWOT (strengths, weaknesses, opportunities, and threats) and SIPOC (Suppliers, Inputs, Process, Outputs, Customer) analyses done
  • Developed process flows to implement a pathway to diagnosis, counseling and referral to interventions
  • Training in implementation science and clinical tools was provided by CPF
Clinical Setting

- NICU and HRIF Clinic in Westwood, CA
- NICU and HRIF Clinic in Santa Monica, CA
Population

- Infants who qualify for HRIF based on CCS criteria identified during their NICU stay
- Infants who did not qualify for HRIF but had an abnormal GMA in the NICU
Training

• Equip HRIF Staff with the Appropriate Tools

GMA
- Physical Therapists
- Occupational Therapists
- MDs (Neo and DBP)

HINE
- Physical Therapists
- Occupational Therapists
- MDs (Neo and DBP)

TIMP
- Physical Therapists
- Occupational Therapists

Appointment is made through scheduling center before NICU discharge

Visit 1
Age Range: 6-9 mo
Personnel: PT/OT, Dietician, Neo team
Testing: BSID, Neuro Exam

Visit 2
Age Range: 12-16 mo
Personnel: PT/OT, Dietician, Neo team
Testing: BSID, Neuro Exam

Visit 3
Age Range: 22-26 mo
Personnel: PT/OT, Dietician, Neo team
Testing: BSID, MCHAT, Neuro Exam

Visit 4
Age Range: 33-36 mo
Personnel: PT/OT, Dietician, Neo team
Testing: BSID, Neuro Exam

- Patient Graduation
- Connect patients to services as needed
Team NEMO reviews the recorded GMAs weekly and flags babies that are 34-38 weeks CGA who need a GMA and do not qualify for HRIF Clinic. Notify parents that their babies need a GMA in the NICU.

• Record the GMA videos on an iPad
  *Video consent form was added to the overall NICU packet that families sign when they are admitted

Team NEMO reviews the recorded GMAs weekly. Study coordinator upload videos onto Redcap for Dr. Maitre to review/confirm findings. Study coordinator maintains Excel Sheet with identifiers.

Abnormal GMA – Team NEMO will communicate findings to the NICU attending on service, who will talk to the family.

Normal GMA – Patient is discharged per usual protocol.

Schedule HRIF Appointment

Visit 1
Age Range: 3-4 mo CGA
Personnel: DBP, PT/OT, Neo
Testing: GMA, HINE, TIMP, BSID

Visit 2
Age Range: 9-12 mo:
Personnel: DBP, PT/OT, Neo
Testing: HINE, BSID

Visit 3
Age Range: 22-26 mo
Personnel: DBP, PT/OT, Neo
Testing: BSID, MCHAT, Neuro exam

Visit 4
Age Range: 33-36 mo
Personnel: DBP, PT/OT, Neo
Testing: BSID, Neuro exam

Additional Visit
Age Range: 6 mo
Personnel: DBP, PT/OT, Neo
Testing: HINE

Additional Visit
Age Range: 18 mo
Personnel: DBP, PT/OT, Neo
Testing: HINE, Targeted exam

Additional Visit
Age Range: 30 mo
Personnel: DBP, PT/OT, Neo
Testing: Targeted exam

Normal

Follow-up phone call to all families that receive a CP diagnosis in clinic.

Abnormal (Absent fidgety, HINE < 57, TIMP below average)

Abnormal
Restructuring the HRIF Clinic Timeline

Before Implementation

HRIF-qualified babies are identified

Babies in the NICU with abnormal GMA

Visit 1: 3–4 months

Visit 2: 12–24 months

Visit 3: 24–36 months

After Implementation

Development and Toddler Development

• GMA
• HINE
• TIMP
• BSID
• Nutrition Assessment
Results

Early Diagnosis of CP Metrics

<table>
<thead>
<tr>
<th>NO OF CP DIAGNOSIS</th>
<th>Pre-implementation</th>
<th>2018-19</th>
<th>2019-20</th>
<th>2020-21</th>
<th>2021-22</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>5</td>
<td>6</td>
<td>4</td>
<td>5</td>
<td>11.42</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10.72</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>9.15</td>
</tr>
</tbody>
</table>
## Results

### High Risk for CP

<table>
<thead>
<tr>
<th>NO OF HIGH RISK FOR CP DIAGNOSIS</th>
<th>AGE AT HIGH RISK FOR CP DIAGNOSIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>3.7</td>
</tr>
<tr>
<td>10</td>
<td>4.05</td>
</tr>
<tr>
<td>6</td>
<td>3.6</td>
</tr>
<tr>
<td>6</td>
<td>3.5</td>
</tr>
</tbody>
</table>

- **Pre-implementation**: Pre-2020
- **2018-19**: 2018-2019
- **2019-20**: 2019-2020
- **2020-21**: 2020-2021
- **2021-22**: 2021-2022
Results

Writhing age GMA in NICU

GMA IN NICU

- 2017-2018
- 2018-19
- 2019-20
- 2020-21
- 2021-22

- 0
- 70
- 93
- 146
- 196
Years 2-5 after initial implementation

• Inpatient Team NEMO consult in NICU: GMA and counseling on need for neurodevelopmental follow-up and early intervention

• Expanding implementation at other UCLA affiliated NICUs

• Improving access to early intervention services:
  • UCLA Intervention Program, Regional center
  • Building collaborative relations in the community: USC Motor Development Lab/ EI3 Collaborative
Team NEMO In-patient consult

NICU Follow-Up INFO SHEET

You and [NAME] are invited to the UCLA Hospital’s NICU Follow-Up Clinic. The purpose of this clinic is to review your child’s developmental progress after discharge from the NICU. We will see your baby in the NICU Follow-Up Clinic for an appointment when they are 3-4 months corrected age.

**Appointment**
- **Date:** Tuesday – [MONTH] [DAY], 2022
- **Time:** 1:00 PM
- **Location:** 200 Medical Plaza
  Suite 265 (2nd Floor)
  Children’s Health Center
- **Duration:** Please plan for 1.5 to 2 hours

**What to Expect**
- Video of General Movements
- Neurologic Assessment
- Physical Therapy Assessment
- Developmental/Psychology Assessment
- Nutrition Assessment

**Regional Center**
Regional Centers offer a wide array of services for California residents to monitor developmental growth. Please contact your regional center for an in-home assessment and to receive services for your baby.

**Your Regional Center:** Westside Regional Center
**Address:** 5901 Green Valley Circle, Suite 320
Culver City, CA 90230
**Phone Number:** 310-258-4000
**Website:** [https://westsideero.org](https://westsideero.org)
This can take up to 6-8 weeks to schedule. Please call as soon as possible.
Question 1 – Do you know why this appointment was especially made for your baby?

- Pre-NEMO Consult:
  - Yes: 41%
  - No: 59%

- Post-NEMO Consult:
  - Yes: 10%
  - No: 90%

Question 2 – Did anyone explain to you what the High Risk Infant Follow-Up Clinic is?

- Pre-NEMO Consult:
  - Yes: 22%
  - No: 78%

- Post-NEMO Consult:
  - Yes: 100%
  - No: 0%
Question 3 – Do you know how long the appointment lasts for?

Pre-NEMO Consult

- Yes: 41%
- No: 59%

Post-NEMO Consult

- Yes: 68%
- No: 32%

Question 4 – Did anyone tell you about the General Movements Assessment (GMA)?

Post-NEMO Consult

- Yes: 86%
- No: 14%
Impact of NEMO Consult – Connecting to EI services

<table>
<thead>
<tr>
<th>Service</th>
<th>PRE</th>
<th>POST</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connected to regional center</td>
<td>52%</td>
<td>80%</td>
</tr>
<tr>
<td>Connected to regional center</td>
<td>77%</td>
<td>100%</td>
</tr>
<tr>
<td>Connected to EI (V1)</td>
<td>41%</td>
<td>56%</td>
</tr>
<tr>
<td>Connected to EI (V2)</td>
<td>70%</td>
<td>94%</td>
</tr>
</tbody>
</table>
Parent Support in HRIF

Parents are screened using Perceived Stress Scale during each HRIF visit by the psychologist.

Based on the parent responses, the psychologist then provides:

- Brief therapeutic intervention in the clinic
- Psychoeducation
- Referrals to UCLA or other community mental health resources for psychotherapy

Follow up phone calls a week after HRIF visit for families that receive a CP (or other) diagnosis and additional diagnoses specific resources.
Impact of Covid-19 pandemic

• HRIF clinics switched to telemedicine
  
  • Parents instructed to take GMA videos at home at 3-4 mo CGA and send the videos to us → lots of technical challenges
  
  • HINE assessments done via telemedicine (support through CPF network)
  
  • Challenges: connectivity issues, set-up at patient’s home not always ideal for neuro developmental assessments, communicating high risk for CP/CP diagnosis via telemedicine
  
  • Increased patient volume in HRIF clinic due to closures/ limitations at other sites
Impact of Covid-19 pandemic

- Inpatient NEMO consults also switched to telemedicine

- Greatly increased show rate and parent availability

- Parents able to join from home and seemed more relaxed in their home environment

- Some NEMO consults done as outpatient 1-2 weeks after discharge - important touch point as many parents had questions about feeding or requested mental health support
Lessons learned

• Change is really hard!
  - Support from leadership and funding help to get started
  - It’s a team sport!!

• Sustaining change
  - Billing for services
  - Training NICU staff in taking/ requesting GMA videos from parents
  - Using MyChart to communicate with families about GMA videos
  - EMR documentation of GMA flowsheet in NICU
  - GMA consultation/ second opinion support through EDI-CPF network
## Lessons Learned

<table>
<thead>
<tr>
<th>Communication</th>
<th>Access to Early Intervention</th>
<th>Community Connections</th>
</tr>
</thead>
</table>
| Communicating an early diagnosis of CP/high-risk for CP can be challenging  
  • Parental anxiety around GMA/getting bad news  
  • Parent support during and after receiving the diagnosis is very important | Improving access to early intervention  
  • Using the GMA to advocate for services | Making connections within our health system and in the community for improved family support and early intervention |
Summary

- Team NEMO successfully implemented the guidelines, leading to a decrease in average age of cerebral palsy diagnosis to under 12 months and early identification of “high-risk for CP”
- Changes have been sustained over the 4 years since initial implementation, despite challenges due to the pandemic
- Increased awareness of need for parental support led to improvements in overall clinical care
Future Directions

- Continue to optimize implementation in NICU and HRIF clinics
- Improve access to early intervention services for babies at high risk for CP
- Trauma informed care in the NICU - using a strength-based approach to promote positive parenting
- Increasing parent mental health support in NICU and HRIF – working synergistically with other systems of care within UCLA and in the community


• Morgan et al. Early Intervention for Children Aged 0 to 2 Years With or at High Risk of Cerebral Palsy: International Clinical Practice Guideline Based on Systematic Reviews. JAMA Pediatr. 2021 Aug 1;175(8):846-858.

• Novak et al. Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy: Advances in Diagnosis and Treatment. JAMA Pediatr. 2017 Sep 1;171(9):897-907.
Acknowledgements

Moira Szilagyi, MD
Chief, Developmental Behavior Pediatrics

Suhas Kallapur, MD
Chief, Neonatology

Cerebral Palsy Foundation