## International Dementia with Lewy Bodies Conference Patient and Care Partner Track December 2-3

## Tuesday, December 1 **Pre-Conference:** Scientific DLB Review and Update

Patients and Care Partners are invited to attend any or all of the scientific sessions on this day. The content will be complex and highly scientific. A special evening session provides an opportunity to ask questions and discuss key messages of the day. This is an optional day and separate registration is required.

| Time         |                                                                                                                                                       | Speaker                                                                |
|--------------|-------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------|
| 7:30 AM -    | Please refer to the Scientific Program for session details                                                                                            | National and International                                             |
| 4:45 PM      |                                                                                                                                                       | Scientists.                                                            |
| 5:30-6:45 PM | The Day Decoded A special Q & A for patients and care partners who registered for and attended any of the Scientific Track Sessions. Dinner provided. | Tanis Ferman, PhD Mayo Clinic Gregory Jicha, MD, PhD Univ. of Kentucky |

## Wednesday, December 2 Day 1: Patient and Care Partner Track

|                                   | Speaker                                                                   |  |  |  |
|-----------------------------------|---------------------------------------------------------------------------|--|--|--|
| Breakfast, Registration, Check-in |                                                                           |  |  |  |
| Welcome                           | Paul Primakoff                                                            |  |  |  |
|                                   | Living with DLB                                                           |  |  |  |
|                                   | Angela Taylor                                                             |  |  |  |
|                                   | Lewy Body Dementia Association                                            |  |  |  |
|                                   | (LBDA)                                                                    |  |  |  |
|                                   | Angolo Lundo                                                              |  |  |  |
|                                   | Angela Lunde<br>Mayo Clinic                                               |  |  |  |
|                                   |                                                                           |  |  |  |
| Session 1: THE SCIENCE            |                                                                           |  |  |  |
| Setting the Stage: A DLB Primer   | Erin Golden, MD                                                           |  |  |  |
|                                   | Mayo Clinic                                                               |  |  |  |
| DLB Clinical Distinctions         | Gregory Jicha, MD,PhD                                                     |  |  |  |
|                                   | Univ. of Kentucky                                                         |  |  |  |
| DLB Neurological Causes           | Jennifer Molano, MD                                                       |  |  |  |
| -                                 | Univ. of Cincinnati                                                       |  |  |  |
|                                   | Session 1: THE Session the Stage: A DLB Primer  DLB Clinical Distinctions |  |  |  |

| Session 2: THE DIAGNOSIS & MANAGEMENT                       |                                                                                                                  |                                                                               |  |  |
|-------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------|--|--|
| 10:35 -12:15<br>PM                                          | Making the Diagnosis                                                                                             | Jonathan Graff-Radford, MD<br>Mayo Clinic                                     |  |  |
|                                                             | Symptom Management                                                                                               | Gregory Jicha, MD, PhD<br>Univ. of Kentucky                                   |  |  |
|                                                             | The Patient and the Family                                                                                       | James Galvin, MD, MPH Florida Atlantic University                             |  |  |
|                                                             | Q&A Sessions 1 & 2                                                                                               | James Galvin Erin Golden Jonathan Graff-Radford Gregory Jicha Jennifer Molano |  |  |
| 12:15-1:30                                                  | Lunch                                                                                                            |                                                                               |  |  |
| PM Session 3: THE STRUGGLES AND THE STRATEGIES              |                                                                                                                  |                                                                               |  |  |
| 1:30-3:00                                                   | Separate gatherings for education, support and peer to pe  Persons living with Lewy body dementia  Care Partners |                                                                               |  |  |
| 3:10-3:30                                                   | Reflections                                                                                                      | Ashley Bayston<br>The Lewy Body Society, UK                                   |  |  |
|                                                             |                                                                                                                  | Debbie Richman<br>Alzheimer's Association and Related<br>Dementias            |  |  |
|                                                             | CONNECTING                                                                                                       |                                                                               |  |  |
| 3:30- 4:30                                                  | Rest, Relax, Mingle                                                                                              |                                                                               |  |  |
| 4:30-5:00                                                   | Research Posters Guided Tour                                                                                     |                                                                               |  |  |
| 5:00-6:30                                                   | Wine and Cheese Reception with the Scientists                                                                    |                                                                               |  |  |
| Thursday, December 3  Day 2: Patient and Care Partner Track |                                                                                                                  |                                                                               |  |  |
| Time                                                        |                                                                                                                  | Speakers                                                                      |  |  |
| 7:30-9:00 AM<br>7:45-8:45                                   | Registration, Check-in Optional –Critical Conversations over Breakfast                                           |                                                                               |  |  |
| 9:00-9:25                                                   | Welcome                                                                                                          | Diana Myles<br>Care Partner                                                   |  |  |
|                                                             |                                                                                                                  | Ian McKeith, MD, F Med Sci<br>Newcastle University, UK                        |  |  |
|                                                             |                                                                                                                  | Angela Lunde<br>Mayo Clinic                                                   |  |  |

| Session 4: THE EXPERIENCE |                                                                                                                                                                                                                                                                      |                                                                        |  |  |
|---------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------|--|--|
| 9:25-10:10                |                                                                                                                                                                                                                                                                      | Alexander Dreier<br>Living with DLB                                    |  |  |
|                           |                                                                                                                                                                                                                                                                      | Olivia Dreier<br>Care Partner                                          |  |  |
|                           |                                                                                                                                                                                                                                                                      | Paul Smith<br>Care Partner                                             |  |  |
| Session 5: THE RESEARCH   |                                                                                                                                                                                                                                                                      |                                                                        |  |  |
| 10:25-11:35               | Steps Forward in Research                                                                                                                                                                                                                                            | Brad Boeve, MD<br>Mayo Clinic                                          |  |  |
|                           | <ul> <li>Featured Poster Presentations</li> <li>Principles for managing Lewy body dementia: patient and carer perspectives from the DIAMOND-Lewy study</li> <li>The effect of exercise on individuals with Dementia with Lewy Bodies: A systematic review</li> </ul> |                                                                        |  |  |
|                           | Q & A Sessions 4 & 5                                                                                                                                                                                                                                                 | Brad Boeve, MD plus poster presentation presenters                     |  |  |
| 11:35 -12:35<br>PM        | Lunch                                                                                                                                                                                                                                                                | F                                                                      |  |  |
|                           | Session 6: THE THERAPIES                                                                                                                                                                                                                                             |                                                                        |  |  |
| 12:35-2:45                | Evidence Based Therapies for Caregivers & Patients                                                                                                                                                                                                                   | Steven Zarit, PhD Penn State University & Jonkoping University, Sweden |  |  |
|                           | Team Based Care                                                                                                                                                                                                                                                      | James Galvin, MD, MPH<br>Florida Atlantic University                   |  |  |
|                           | Healthy Actions to Benefit Independence and Thinking                                                                                                                                                                                                                 | Julie Fields, PhD<br>Mayo Clinic                                       |  |  |
|                           | Cultural Arts as an Intervention in Dementia Care                                                                                                                                                                                                                    | Kate DeMedeiros, PhD<br>University of Miami                            |  |  |
|                           | Therapies Q & A Panel                                                                                                                                                                                                                                                | Steven Zarit, James Galvin Julie Fields Kate DeMedeiros                |  |  |
| Session 7: THE HOPE       |                                                                                                                                                                                                                                                                      |                                                                        |  |  |
| 3:00-4:20                 | A Mindful Journey                                                                                                                                                                                                                                                    | Marguerite Manteau-Rao, LCSW<br>Presence Care Project                  |  |  |
|                           | A Call to Action                                                                                                                                                                                                                                                     | Angela Taylor                                                          |  |  |
|                           | Closing Remarks                                                                                                                                                                                                                                                      | Paul Primakoff                                                         |  |  |
| 6:30-10:30                | Optional Evening Activities                                                                                                                                                                                                                                          |                                                                        |  |  |